DEPARTMENT OF LEARNING, INFORMATICS,
MANAGEMENT, AND ETHICS
Karolinska Institutet, Stockholm, Sweden

NEGATIVE EXPERIENCES OF ENCOUNTERS IN HEALTHCARE

Maja Wessel

Karolinska Institutet

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To my family

ABSTRACT

A positive encounter is essential to the provision of qualitative healthcare. Experiences of negative encounters in healthcare may affect the patient's wellbeing and health, and have a negative effect on the patient's trust in the healthcare system. The overall aim of this thesis was to gain new knowledge about negative experiences of encounters in Swedish healthcare and, based on this knowledge, suggest potential measures to reduce or prevent such experiences. The thesis consists of four different studies:

STUDY 1

Aim: To investigate patients' experiences of not being treated well in medical healthcare in Stockholm County, Sweden. **Methods**: Systematic review of complaints of negative encounters to Patientnämnden in Stockholm registered in 2006 and 2007. The complaints were subjected to qualitative content analysis by categorization, and a complementary snapshot review of complaints on medical treatment was conducted. **Results**: The most common types of complaints were "rude, aggressive or arrogant behaviour", followed by "being ignored, not listened to, or being taken seriously". One third of the complaints about "medical treatment" also contained complaints about negative encounters. Women were found to complain on negative encounters more frequently than men.

STUDY II

Aim: To examine how long-term sick-listed persons perceive healthcare encounters, with special emphasis on negative encounters and feeling wronged. **Methods**: Postal questionnaire to 10 042 long-term sick-listed persons. Statistical analysis of Attributable Risk (AR) with 95% CI. **Results**: Response rate 58%. 1 628 of the respondents had experiences of negative encounters in healthcare, and of these 1 036 reported also having felt wronged. Types of negative encounters with highest AR for feeling wronged were "nonchalant behaviour" and "treated me with disrespect". Men reported higher AR for feeling wronged than women, as did respondents with psychiatric diagnoses compared to other patients. Feeling wronged seems to be an outcome based on accumulated experiences of negative encounters.

STUDY III

Aim: To gain an improved understanding of experiences of negative healthcare encounters in the general population. **Methods**: Postal questionnaire to a sample of 1 484 inhabitants of Stockholm County. Conventional content analysis of data from open-ended questions. **Results**: Response rate 62.1%. 17 different types of complaints about negative encounters were identified and two comprehensive explanatory factors were established: "structure and allocation of healthcare" and "the staff's attitudes and professional practice".

STUDY IV

Aim: To investigate the hypothesis that complaints of adverse events related to encounters with healthcare personnel are underreported, and to identify barriers to filing such complaints. **Methods**: Postal questionnaire to a sample of 1 484 inhabitants of Stockholm County. Statistical analysis of proportions and OR with CI: 95%, and minor qualitative content analysis by categorization. **Results**: Response rate 62.1%. Patient complaints about negative encounters were found to be under-reported. The main barriers for filing complaints were "did not have the strength" or "did not know where to turn", or that "it makes no difference anyway". Experiences of negative encounters were also found to have a negative impact on people's trust in healthcare.

LIST OF PUBLICATIONS

I. Wessel M, Helgesson G, Lynöe N. Experiencing bad treatment: Qualitative study of patient complaints concerning their reception by public healthcare in the County of Stockholm. Clinical Ethics 2009;4:195-201.

II. Wessel M, Helgesson G, Olsson D, Juth N, Alexandersson K, Lynöe N. When do patients feel wronged? Empirical study of sick-listed patients' experiences with healthcare encounters. European Journal of Public Health 2013 Apr; 23(2):230-5. doi: 10.1093/eurpub/cks030.

III. Wessel M, Lynöe N, Juth N, Helgesson G. Bad apples or bad barrels? Qualitative study of negative encounters in healthcare among the general population. Manuscript.

IV. Wessel M, Lynöe N, Juth N, Helgesson G. The tip of an iceberg? A cross-sectional study of the general publics' experiences of reporting healthcare complaints. BMJ Open 2012:2:e000489.doi10.1136/bmjopen-2011-000489.

RELATED PUBLICATIONS

Lynöe N, Wessel M, Olsson D, Alexanderson K, Helgesson G. Respectful encounters and return to work: empirical study of long-term sick-listed patients' experiences of Swedish healthcare. BMJ Open 2011 Jan 1;1(2) doi:10.1136/bmjopen-2011-000246.

Lynöe N, Wessel M, Olsson D, Alexandersson K, Tännsjö T, Juth N. Are patients duelling with doctors in order to restore their honour? Empirical study of sick-listed patients' experiences of negative healthcare encounters with special reference to feeling wronged and ashamed. Journal of Medical Ethics 2013 Feb 2. doi: 10.1136/medethics-2012-100871.

Lynöe N, Wessel M, Olsson D, Alexandersson K, Helgesson G. Does feeling respected influence return to work? Cross-sectional study on sick-listed patients' experiences of encounters with social insurance office staff. BMC Public Health. 2013;13:268 Mar 23 doi:10.1186/1471-2458-13-268.

CONTENTS

LIST OF ABBREVIATIONS

AR	Attributable Risk
CI	Confidence Intervals
HSAN	Hälso- och sjukvårdens ansvarsnämnd
OR	Odds Ratio
PaN	Patientnämnden (Patient's Advisory Committee)
RTW	Return to work

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PROLOGUE

When I introduce myself and my field of research to new people I am always astonished by the many personal stories I am told about negative healthcare encounters. Many times I have also been surprised by the openness with which these situations are described, by persons who as yet are strangers to me. Their stories are often intimate, at times emotional, and sometimes they clearly transgress common social norms regarding social interaction between people who are not close relatives or friends. Not everyone wants to share experiences, but many are curious or wish to express their opinion in the matter. Clearly, the subject of healthcare encounters gives rise to an interest beyond the academic and seems to affect people emotionally.

The reason I became involved in research about healthcare encounters is that I believe that this is part of what constitutes the foundation for a secure, efficient and humane healthcare system. It may seem obvious to some, but increased complaints about how patients are encountered indicates that this view might not be shared by all. In this thesis I wish to expand the level of existing knowledge in the field, and to some extent discuss underlying factors which may lead to negative experiences of healthcare encounters. Most of the studies included in the thesis were conducted in Stockholm County, but many of the research topics and findings may just as well be relevant in other contexts. I hope that this thesis will serve as a reminder of how important the healthcare encounter can be and also offer some guidance on how to prevent negative experiences of encounters. If this should lead to at least one less future complaint, I believe my research to have proven its value.

1 BACKGROUND

The topic of this thesis is one that almost everyone can relate to. We have all been in contact with healthcare in one way or another and we all expect to be taken care of when we get ill, at least in countries maintaining a fairly comprehensive public healthcare system such as Sweden, which is also the country at the centre of this thesis.

Every year, there are more than 65 million healthcare visits in Sweden, and the majority take place in primary care. About 16 million of them occur in Stockholm County, which is also the region with the highest number of healthcare visits per person: on average a citizen of Stockholm visits healthcare 8 times per year. The national average is 6.9 healthcare visits.[1] Most of the time these meetings proceed well and the patient in question feel adequately treated and satisfied with the encounter.

Most people also seem to have a high level of trust in the healthcare system and the persons working within it. A recent survey in Sweden has shown that a majority state to have confidence in physicians (79%) and nurses (84%).[2] This positive attitude towards healthcare staff is, however, not limited to Sweden. Similar results have been obtained also in a comprehensive cross-national survey conducted in India, the USA, Brazil, Colombia, and 15 European countries, which confirms a generally high level of confidence in healthcare professionals, only exceeded by confidence in firefighters and teachers (average for all countries).[3]

Returning to Sweden – more specifically, to the capital city of Stockholm – there is also, according to an annual survey conducted by the County Council (SLL), confidence in that the generally positive opinion of the organization of healthcare show a rising trend.[4] In 2010 about 86% of a sample of citizens responded that they were pleased or very pleased with healthcare in Stockholm. And according to the report, the prospects of a further positive rise in public confidence are rated good.[4] Yet, every year, the number of complaints concerning different aspects of healthcare increases.[5]

1.1 THE HEALTHCARE ENCOUNTER

It is important to receive adequate treatment when ill, but this is not the only thing that affects the patients' experience of the healthcare services. Another important aspect is a good relation between the patient and the caregiver. To many, this statement may seem evident: in most societies and social situations you are expected to treat other individuals with respect and consideration, and, arguably, at least by a virtue-ethics-

oriented person, if you fail in this you fail in your basic duty as a human being. [6] In Swedish healthcare a respectful encounter is actually a formal requirement, based on the principle of universal human equality.[7] However, there might be those who oppose such a view, maintaining that the only thing of relevance is receiving adequate medical treatment. The behaviour of healthcare staff is of minor importance, or none at all, and likewise the patient's possibility to participate in decisions regarding their own care is considered as of lesser importance. Possibly, this view can sometimes also be held by caregivers. We have, after all, a long tradition of paternalistic medical practice, and it is not unthinkable that some parts of this tradition may still prevail in some settings, although attitudes have changed dramatically during the last century.[8,9]

Either way, the great majority of the population in Stockholm seems to have positive experiences of encounters with healthcare professionals.[10] Examples of what aspects characterizes a positive encounter is being listened to, being taken seriously, and being met with empathy, all of which are acclaimed social factors in most social settings.[11–14] I will return to this below.

A noticeable trend in Sweden is that the term "kränkt" (wronged) has become increasingly common in the public discourse as well as in relation to healthcare encounters. [15,16] For example, compared with ten years ago, police complaints regarding defamation (ärekränkning) have almost doubled; in 2002 there were 6 389 complaints compared to 11 508 complaints during 2011.[17] A suggested explanation for this vast increase is that many reports can be put down to the increased use of internet forums and social media where people can communicate while remaining confidential.[18] Probably more social transgressions and attacks will occur in a forum where the offender is not easily held responsible for such statements, compared to the non-virtual world. However, the internet alone does not explain the increased number of reports of feeling wronged, nor does it explain why the occurrence of such complaints is increasing in the healthcare setting.

Negative experiences of encounters in healthcare may be more common than we think. At least, this is the impression conveyed in recurrent media reports of poor conditions and patients' testimonies concerning abusive and disrespectful treatment in healthcare.[19–21] If this is true, does it mean that patients are being treated in a more negative manner today? Complaints on negative healthcare encounters is arguably a valuable source of information about patients' experiences of Swedish healthcare, and

by learning more about them we can add to the foundation for a continuously high-qualitative healthcare system in Sweden.

Although the field of research regarding healthcare encounters is expanding, still little is known about how the general public perceives healthcare encounters per se. The overall aim of this project is to learn more about peoples' experiences of negative encounters by studying descriptions of encounters in Swedish healthcare. The studies included in this thesis are focused on the perspective of the patient, and does accordingly not problematize the acts and behaviours of patients that may also affect how the encounter evolves.

Moreover, this is a thesis originating in Medical Ethics, which enables a normative discussion, i.e. a discussion of moral conceptions and ethical positions in relation to the healthcare encounter.

1.2 THE SWEDISH HEALTHCARE SYSTEM: THE PATIENT IN THE CENTER

In a historical context, patients, with few exceptions, have not enjoyed the same status as they do today. The patient–physician relationship in particular has traditionally been characterized by an unequal power balance, whereby physicians have often made medical decisions on behalf of the patient, without conferring with the patient or asking for consent. [8, 22]

The asymmetric power relation is in some respects an inevitable feature of healthcare, partly since patients are weakened by their condition and partly since healthcare professionals possess medical knowledge that patients do not. [23] In Sweden, however, demands for strengthening of the patients' position have been reinforced during the past decades.[24–27] The contemporary healthcare legislation stipulates that "Care shall be provided with respect for the equal worth of all persons and for human dignity" and "founded on respect for patient autonomy and integrity"[7] (author's translation). Thus, a respectful encounter is a clearly defined requirement in healthcare. Swedish healthcare nowadays requires that patients, to the extent that they are capable, be invited to participate in decisions about their own care.[28] The patients' right to understandable information has been highlighted as a main factor in achieving this. It has also been stressed that the provider of the information needs to control and confirm that the information has been properly understood.[29]

So, the role of today's healthcare provider entails ensuring that the patient is well informed, so that he or she can make informed choices, and supplying the kind of information the patient needs and requests. The healthcare provider also needs to find out as much about the patient's condition as possible in order to determine the right diagnosis, at the same time as he or she must be careful not to violate the patient's integrity with the questions asked. For the caregiver it is sometimes difficult to know how to approach the patient; some patients want to have all available information and actively control each step of their way through the healthcare system, other patients prefer to leave all decisions to the physician or nurse treating them, while most patients end up somewhere in between.[30], [31] Some patients are comfortable with openly sharing sensitive details about themselves, while others are not. These examples are but a few of many factors characterizing the complex interplay between the healthcare provider and the patient and which may cause misunderstandings, but they illustrate well the complicated nature of the healthcare encounter.

One can assume that many conflicts between patients and healthcare providers are never "detected" by a third party or officially registered. Many patients lack the energy or interest to proceed with their case once they are well again, and prefer perhaps simply to avoid that particular caregiver in the future. Others patients have complained at the site, and the compliant have been managed by the persons responsible once the problem has been revealed. Such complaints also escape official registration.

1.2.1 Reporting complaints

1.2.1.1 *Socialstyrelsen, HSAN, and Patientförsäkringen*

To complain about healthcare, the patient is primarily advised to contact the manager of the department of the hospital or clinic where the incident occurred. The department concerned is required to investigate the claim. However, there are also a number of official agencies to which the patient can turn. These public agencies have the mission to develop and maintain quality in healthcare, and great efforts have been made to build supportive systems that assist patients in reporting malpractices and adverse events. For complaints regarding health inquiry or patient safety one can contact Socialstyrelsen (the National Board of Health and Welfare, henceforth referred to in Swedish) for investigationof the event. Socialstyrelsen may forward the claim to HSAN (Hälso- och sjukvårdens ansvarsnämnd, the Medical Responsibility Board) if it requires legal examination. HSAN was set up in 1980 and has the authority to withdraw a physician's

licence to practise or to adjudge suspension if the defendant is convicted. The patient may also turn to the Swedish Patient Insurance (In Swedish: Patientförsäkringen) for financial compensation if they are injured in healthcare.*

1.2.1.2 *Patientnämnden*

For complaints about encounters, the patient or the patient's family members have since 1999 been referred to The Patients Advisory Committee (Patientnämnden (PaN); henceforth referred to in Swedish).†,[32] The function of PaN is to assist and support individual patients by conveying their complaints to the appointed caregiver or clinic and to manage their responses, which then are conveyed to the complainant. More specifically, PaN's mission is to maintain quality and high patient safety in health care by

- providing information,
- promoting contacts between patients and healthcare professionals,
- guiding patients to the right authority,
- reporting deviations and observations of importance for patients to the healthcare providers and healthcare units in question. †

PaN is an independent and impartial institution at county level with a proactive emphasis. PaN is not authorized to award penalties, but will mediate between the patient and the healthcare professional. The healthcare professional is obliged to respond to the complaint, and according to PaN, about 80% of the complaints are settled after a first response has been communicated.[5]

Most complaints to PaN concerns physicians. The complaints that were reported to PaN in 2010 and could be attributed to a specified person or function in healthcare (around 70 per cent) revealed that the majority of these complaints, 72 per cent, involved physicians, followed by complaints against nurses (9 per cent), and dentists (8 per cent). The remaining 11 per cent concerned a large number of other professions and functions.[33]

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* Lex Maria reports are not included in this section, since such reports can not be initiated by a patient.

† Until 2011 it was also possible to lodge complaints regarding negative encounters to Socialstyrelsen but after recent reorganizations all such claims are managed by PaN, unless they are investigated by HSAN.

As the above description shows, Sweden has developed an extensive system for handling errors in healthcare and for promoting quality improvement and patient safety. Yet discontent and the number of complaints are increasing every year.[10] Similar trends are also seen in our neighbouring countries Finland, Denmark, and Norway. [34–36]

1.3 PREVIOUS KNOWLEDGE ABOUT ENCOUNTERS IN HEALTHCARE

1.3.1 Positive and negative encounters

A review of previous reports of patients' perceptions of positive and negative encounters in Sweden shows that a positive healthcare encounter is characterized in terms of being listened to, feeling included, feeling confirmed, feeling empathy, and feeling supported.[37–41] The list of what constitutes negative experiences of encounters is more or less an inverted version of the above-listed features: not being listened to, not being taken seriously, lack of information, feeling treated like an object and not an individual, arrogant or aggressive behaviour, and not having one's integrity respected are recurrent examples of negative patient experiences.[10],[15],[37],[42–44]

1.3.2 The patient-caregiver relation and health outcomes

A positive encounter may enable the patient and the caregiver to establish a good relation. Even though healthcare services generally are appreciated in Sweden,[10] there are many occasions when conflicts arise. Cultural differences, language problems, difficulties in understanding each other (for example regarding intentions, or use of metaphors), power imbalance, failure to meet the patient's expectations, and gender are some factors suggested as potential causes of conflict and for patients' experiences of negative encounters. [14],[41],[45–47]

The importance of the patient-caregiver relationship is often highlighted in litterature. By and large, good relations rely on good communication, and the significance of communication is accordingly illuminated in many studies.[48–53] Much of the literature offers support for the putative relationship between good communication and a patient-centred, harmonious, inclusive, and supportive relation between the caregiver and the patient. Such a positive relation may in turn have a positive impact on the patient's adherence to treatment or therapeutic compliance, as well as positive outcomes in terms of patient satisfaction, safety, and wellbeing. [48],[52],[54–56] Several studies also support the idea that the quality of the patient-physician relation may affect the patient's health status, and point to the relevance of both

positive and negative experiences of encounters for the patients' health.[48,57] Associations have for example been reported regarding diabetes, cancer, acute tonsillitis and chronic disease.[58–63]

1.3.3 Gender

According to the report "Jämställda klagomål (Equal complaints)"[44] presented by SLL in 2006, women report 17% more complaints on healthcare compared to men in Sweden (adjusted for the overall healthcare consumption). Similar differences have also been found internationally.[64,65] According to the report most complaints were about medical treatment, of which 64% originated from women. However, the type of complaint with the greatest gender difference concerned "bemötande", i.e. negative encounters with healthcare personnel, where 72% of the complaints came from women. According to the report women complain in particular of not being listened to and not being taken seriously.[44]

Recent studies in Sweden have focused on the fact of women being exposed to negative encounters more often than men, and on the risk of a negative encounter aggravating the experience of suffering in healthcare.[43,47,66] To address such issues, a more "gender-sensitive care" has been proposed.[65,67,68] However, the validity of women's complaints has also been questioned. For example, one study conducted in Sweden by Pukk et al.[69] which presents "strong evidence that there are both gender and age differences in the filing and adjudication of malpractice claims"[69] also critically discusses this phenomenon of women complaining more often than men. While not actually propounding the idea, the authors do not exclude that the explanation to the higher complaint rates may be that women simply have a lower "complaint threshold"[69] However, it is also known that women more often suffer medical complications and errors in treatment of for example cardiovascular disease, cancer, and renal disease than men.[70–72] This gender difference could also provide a credible explanation for at least part of women's higher degree of complaints on healthcare.

1.3.4 Age

Age has been found to be a predictor for healthcare complaints, with young adults and middle-aged persons lodging complaints more often than older persons. [10,15,69] For example, one study holds that older persons, aged ≥80 years lodged complaints about five times less often than patients aged 40 to 59 years.[69] One reason could be different

patterns of behavior and expectation on participation depending on the patient's age. Studies have for example shown that elder patients are less likely to actively seek information about their conditions from healthcare staff but more likely to want healthcare to make health-related decisions for them than younger patients do.[73,74] Such behavioural differences may possibly explain lower complaint rates, in particular complaints regarding poor information, participation, and on not being listened to.

1.3.5 Persons born outside of Sweden

Persons born outside of Sweden have been found to be less content with their healthcare encounters in Stockholm County compared to persons born in Sweden.[10,75] They are also known to respond less frequently to surveys and to have lower healthcare attendance rate.[76,77] However, people born outside of Sweden are also a heterogeneous group, with different cultural dispositions and traditions regarding approaches to healthcare. People born in Latin America and people born in Asia have, for example, been found to exhibit very different healthcare-seeking behaviour when consulting primary care. Generalizations based on a division between "Swedes" and "foreign-born people" in research may thus be too blunt and have been criticized.[78]

1.3.6 "Difficult patients"

One sign of failed healthcare relations is so-called "difficult" patients, i.e. patients who never seem content with their treatment while often having medically unexplained symptoms.[79–81] A common denominator for many of these patients, according to a Danish study, is that they have been wronged by someone at an early stage of their contact with healthcare. This experience of having been wronged has then indirectly caused an extensive subsequent contact with healthcare.[79]

Sharpe et al. list three main categories of patients who are found more difficult to help than others: patients with severe untreatable illness, patients with medically unexplained symptoms, and patients with co-existing social problems.[82] Patients with such ailments are also over-represented in complaints about healthcare, as are patients with psychiatric disorders.[83,84] Since these patients do not feel that they are getting the help they need and will continue to seek help elsewhere in the hope of getting an answer or recognition, or, as argued by Hahn, Feiner and Bellin, to create a "compensatory alliance" in the healthcare setting[84,85] in order to compensate for conflicts or lack of social support from a family or a social network. Yet another

interpretation could be that some patients who continuously seek care may actually be "duelling with doctors" in an attempt to restore their honour.[86]

The lack of a medical explanation or an evident course of treatment for a condition may result in feelings of helplessness, frustration and stress for the caregiver, which sometimes can be aggravated by meeting patients with high expectations and demands.[87] Being unable to help the patient in any other way, the physician may in such situations consider alternative courses of treatment, with the consequence that these patients are often referred to some sort of psychiatric treatment.[88,89]

1.4 BIOMEDICAL ETHICS

1.4.1 Medical ethics

Medical ethics is an interdisciplinary research field that critically studies ethical aspects and conflicts within the field of healthcare and biomedical research.[90] Like all ethics, medical ethics deals with norms and values, i.e., matters of right and wrong, good and bad, but specifically in healthcare and medical research. More specifically there are three main questions of interest for medical ethics. One concerns *values* (what is good or bad, desirable or undesirable?), the other concerns *what we should do* ('which actions are correct and desirable?), and the third is about *who we should be* ('which moral character should we aspire to?').[90] Investigations of healthcare encounters from an ethical perspective mainly concern questions of *what we should do*, and to some extent which *values* are manifested in the healthcare encounter. In practice this means that we can discuss guidelines, practice and experiences, as well as engage in reflections regarding what kind of behaviour is desirable or undesirable, and why this is important.

1.4.2 Normative ethics

Normative ethics represents a part of moral philosophy aimed at solving questions of how we should live and act. There are general normative theories trying to answer these questions, such as for example consequentialism, deontological ethics, or virtue ethics.[91] These theories often aim at establishing which features make actions right or wrong. Accordingly, normative ethics does not primarily focus on empirical issues regarding what actions people *believe or consider* to be right, nor on what *is said* in different regulations or how people actually *do* act. Regarding negative encounters,

normative reasoning is needed to decide whether if, and if so why, some types of encounters in fact are negative, while others are not.

1.4.3 Empirical input in ethical research

In this thesis, when using the term "empirical research" we refer knowledge based on direct or indirect observations or experiences,[92] including both qualitative and quantitative approaches.

The studies included in this thesis are all based on empirical data drawn from either a registry (Study I) or from questionnaires (Study II-IV). It is not possible to derive normative conclusion from descriptive statements without adding normative arguments. However, most normative arguments in practice rest on empirical assumptions, which mean that the validity of the normative argument is partly dependent on facts. Empirical research can also generate normative hypotheses – by saying something about how something is, discussions of how it should be are likely to follow.

Some opponents of empirical ethical research claim that allowing empirical input into ethics opens for a loss of normativity and relativistic interpretations, impeding the researcher from drawing normative inferences.[93],[94] It is, thus, important to recognize that although empirical research cannot answer normative questions, it may be essential for identifying and solving practical problems; for example when assessing which action to take in a specific setting. This is probably a reason for empirical approaches in ethics becoming increasingly recognized by ethicists.[93]

1.4.4 Biomedical principles

Much normative discussion in healthcare is based on Beauchamp & Childress' classical work *Principles of Biomedical Ethics*,[95] which presents a set of moral principles functioning as an analytical framework expressing underlying general values in common morality.[96] Ethics in a healthcare context primarily concerns how the individual patient should be treated, that is, what are the harms and benefits of each action? In many cases this decision is unproblematic, but sometimes ethical conflicts arise.

There are four basic principles for moral action that ought to be considered during the assessment of which action to take in ethically challenging situations;

- the principle of *beneficence* which means that one should (always) try to help the patient by meeting his or her medical as well as humanitarian needs
- the principle of *non-maleficence* which means that one should avoid intentionally inflicting harm to the patient, for example by refraining from undue risk-taking
- the principle of *justice* which means that one should treat equal patients equally. This means that patients with equal needs should receive equal treatment (irrespective of, for example, gender, age, background, or socio-economic status)
- the principle of *respect for autonomy*, which means that one should respect the patient's right to self-determination; this also includes providing the patient with information relevant to these decisions

These are so-called prima facie principles, not absolute principles, meaning that one principle cannot generally be said to trump the other.[97,98] The framework does not in itself constitute a complete ethical system stipulating how to balance the principles against each other in case of internal ethical conflicts. Rather it functions as a reminder of central ethical aspects that all need to be carefully considered when deciding which action is the right one to take in a certain setting.[90] For example, a conflict between the principle of autonomy (which dictates that you should let the patient decide) and the principle of beneficence (which dictates that you should do good to the patient) may arise in cases where the patient rejects an evidence-based recommended treatment or intervention that would probably be successful. How should a medical professional act when encountering such dilemmas? In addition to these four principles there are also some other ethical aspects that may be considered, such as for example respect for personal integrity.[90]

1.5 TERMINOLOGY

1.5.1 Negative encounter

The central term in this thesis is the Swedish term "bemötande", which is defined in terms of behaviour towards someone; i.e., it is concerned with how the other person is treated or received.[99] Unfortunately the term has no exact English equivalent with the same connotations.[100] "Treatment" perhaps comes nearest, but is troublesome to use since in the healthcare context it is usually associated with medical treatment, which is something that the Swedish connotation of "bemötande" does *not* include. Rather it is behaviour towards the patient while examined or (medically) treated, but not including examination and treatment, that "bemötande" is about, i.e., the manner in which the actions are performed and thereby how the patient is met (e.g. amicably, empathically, aggressively, or impatiently). We have – with the exception of Study I, where we used the term "bad treatment" – chosen to apply the term "encounter" to denote the various aspects of behaviour, attitudes, and actions that are expressed and experienced in the meeting between healthcare personnel and the patient.

A philosophical clarification in relation to this may be needed: by asking in surveys about experiences of negative encounters, we cannot learn about what encounters are morally bad, but only about the respondents' perceptions of those experiences.

1.5.2 Wronged

Another central concept, targeted in study II, is "kränkt". This Swedish term also lacks an exact English equivalent. Several English terms, such as "insulted", "abused", "violated", and "offended", may be correct translations, depending on the context. However, all these terms, in themselves, are too narrow in scope to cover all potential applications of "kränkt" in the Swedish language. We have chosen to consistently use the term "wronged", since it is the most comprehensive translation and shares with "kränkt" the implication that something inappropriate and of moral relevance has happened. It may, but does not necessarily, relate to someone having his or her rights disrespected, for example with regards to autonomy, personal integrity, or fairness.

1.5.3 Caregiver

The vast majority of complaints in Swedish healthcare concern physicians, followed by nurses and dentists. Unless of particular importance for a specific situation or example, we have chosen not to specify to which of these professions the included negative experiences of encounters can be attributed. Throughout the thesis we generally refer to "the caregiver" as the term is broad enough to cover all included professions.

2 AIMS OF THESIS

This is an empirically oriented thesis in medical ethics, with both explorative and normative ambitions, but with emphasis on descriptions. The overall aim of this thesis is to gain new knowledge about patients' negative experiences of encounters in Swedish healthcare and, based on this knowledge, to suggest potential means of reducing or preventing such experiences.

Reducing the number of negative experiences of encounters in healthcare is important since it has been shown that such encounters have negative effects on patients' health and wellbeing. The thesis consists of four different studies, each with its specific aims:

Study I: Systematic review of registered complaints of negative encounters to Patientnämnden (PaN), aimed at investigating patient's experiences of not being treated well in medical healthcare in Stockholm County, Sweden.

Study II: Postal questionnaire to long-term sick-listed persons, aimed at examining how these patients perceive healthcare encounters, with a special focus on negative encounters and feeling wronged.

Study III: Postal questionnaire to the general population of Stockholm County, aimed at achieving a better understanding of experiences of negative healthcare encounters in the general population.

Study IV: Postal questionnaire to the general population of Stockholm County with the aim of investigating the hypothesis that complaints over adverse events related to encounters with healthcare personnel are underreported, and identifying barriers to filing such complaints.

3 ETHICAL APPROVAL

3.1 STUDY I, III, IV

Ethical approval was granted by the Regional Ethical Review Board in Stockholm in 2008, Dnr 2008/439-31.

3.2 STUDY II

Ethical approval was granted by the Regional Ethical Review Board in Linköping in 2003, Dnr 03-261.

4 METHODS

4.1 OVERVIEW OF STUDIES

Table 1: Overview of studies

Study	Title and year of publication	Study design	Sample	Analysis
I	Experiencing bad treatment: qualitative study of patient complaints concerning their treatment by public health-care practitioners in the County of Stockholm 2009	Register study Review of registered complaints to PaN	Purposive sample: n=1 248 Registered complaints to PaN in Stockholm County Council during 2006 and 2007	Qualitative content analysis and presentation of proportions
II	When do patients feel wronged? Empirical study of sick-listed patients' experiences with healthcare encounters 2012	Cross-sectional study Postal questionnaire	Stratified proportional sample: n=10 042 Long-term sickness absentees Response rate 58%	Statistical analysis: AR with CI: 95%
III	Bad apples or bad barrels? Qualitative study of negative encounters among the general population in Stockholm County, Sweden (Manuscript)	Cross-sectional study Postal questionnaire	Stratified Sample: n=1 484 The general population in Stockholm Response rate 62%	Qualitative content analysis and minor statistical analysis of frequency and proportions
IV	The tip of an iceberg? A cross-sectional study of the general public's experiences of reporting healthcare complaints in Stockholm, Sweden 2012	Cross-sectional study Postal questionnaire	Stratified Sample: n=1 484 The general population in Stockholm Response rate 62%	Statistical analysis: proportions and OR with CI: 95% and minor qualitative content analysis

4.2 STUDY DESIGN

4.2.1 Study I

In the first study we conducted a systematic review of official complaints of negative encounters to Patientnämnden (PaN) in Stockholm County in 2006 and 2007. Complaints about being treated or received by healthcare staff in a negative manner (labelled "bad treatment" in this study) accounted for 13% of all complaints in 2006 and 2007. These complaints were selected for analysis: n=659/5 062 in 2006 and n=589/4 633 in 2007. In both years, 63% of the complaints about bad treatment originated from women and 37% from men. Information about age or background of the complainants was not available.

The method for analysis was qualitative content analysis by categorization.[101] In addition, a minor complementary presentation of proportions was made.

As a first step, the material was read through a few times by the main researcher, to achieve a comprehensive understanding of the material. Then significant key phrases were selected and coded, and the codes categorized. Thereafter the material was passed over to a second researcher who conducted the same analytical procedure in order to settle a certain level of confirmability. The categorization can be described as an on-going process, as the categories were continuously tried and rejected until a stable set of ten qualitatively distinct and substantial categories, and one additional category containing unspecified complaints on bad treatment, was established. Supportive and illustrative citations describing examples of events were identified and selected for each category.

Finally, the categories were sorted in hierarchic order based on their proportional prevalence. All complaints were included in the analysis, so there was no internal drop-out. Since the data was drawn from an anonymized official report, we did not collect individual consent.

4.2.2 Study II

In 2004 a survey was sent to 10 042 sick-listed persons in Sweden. This survey was a joint project between the faculty of Health Sciences at Linköping University and the department of Clinical Neurosciences at Karolinska Institutet. The aim of the survey was to find out how the respondents had perceived their contacts and encounters with healthcare staff and social insurance officers during their time on sick-leave. The questionnaire contained questions regarding both negative and positive experiences of encounters. See appendix 1.

The selection criteria were being absent for a sick-leave spell that had lasted for 6-8 months and still being registered on 31 December, 2003. The study population was drawn from a register administered by the National Social Insurance Agency and the survey was sent out to a proportionally stratified sample of 10 042 sick-listed persons; 4 011 (40%) men and 6 031 (60%). The questionnaire was mailed to their home address. Two reminders were sent out. The questionnaire had a structured design and contained 22 questions with fixed response alternatives. The questions and response alternatives were based on finding in several preceding empirical studies, theoretical models, and a pilot study.[12],[13],[38],[39],[42],[102],[103]

In the present study we focused on the respondents' answers regarding how they perceived their encounters with representatives of Swedish healthcare. In the questionnaire the respondents were first asked if they had experiences of negative encounters. If they answered affirmatively, they were then asked what kind of behaviours they had been exposed to by choosing from 23 fixed response alternatives; for example, "did not keep our agreements", "interrupted me", or "threatened me". As a third and final step they were finally asked how they had responded emotionally to the negative encounter, given a choice between seven fixed response alternatives; for example, "ashamed", "angry", or "wronged". See appendix 1.

The statistical measure used in study II was Attributable Risk (AR), also known as "population attributable fraction", "population attributable risk proportion" or "attributable fraction".[104] AR has been described as "a useful approach to quantitatively describe the importance of risk factors on the population level. It measures the proportional reduction in (disease) probability when a risk factor is eliminated from the population, accounting for effects of confounding and effect-modification by nuisance variables".[105] In the present study, AR can be interpreted as the fraction of the patients

feeling wronged who would not feel wronged if a particular negative encounter could, for example by intervention, be removed. It takes into account both the prevalence of a type of negative encounter and the strength of the association with feeling wronged. AR was adjusted for gender, age, education, and reason for being sick-listed and presented with 95% confidence intervals (CI).[106] To test the consistency of our results, we also analysed the AR for positive experiences and *feeling respected.*

4.2.3 Study III-IV

Studies III and IV are cross-sectional studies based on a postal survey that was distributed to a sample of the general population living in Stockholm County, Sweden in 2008. The main objective with the survey was to investigate the respondents' experiences of negative encounters in healthcare as patients or as close relatives, and to investigate possible barriers to reporting complaints on negative encounters. The questionnaire also contained additional questions regarding trust and general experience of the Swedish healthcare system.

The questionnaire was developed by the research team. The questions were piloted in the department of LIME, Karolinska Institutet, and were modified twice in order to achieve as clear and balanced formulations as possible.

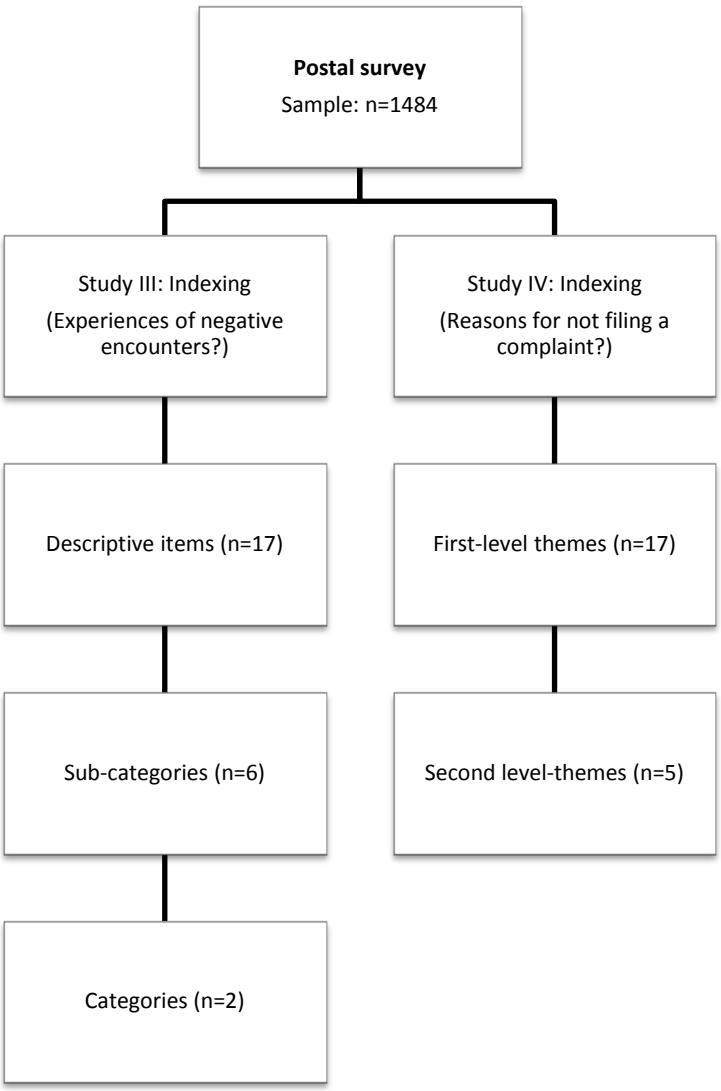
The final questionnaire contained seven questions with fixed response alternatives and room for additional comments, and two questions where the respondents' were encouraged to provide lengthy free-text descriptions of their experiences. See appendix 2. The questionnaire also contained background questions regarding age, sex, and previous experiences of working within the healthcare system. The questionnaire stipulated no restrictions based on time or location for the acquired experience.

The questionnaire was distributed to a stratified sample of the population consisting of 1 484 persons (50% women and 50% men, aged 18-89 years) registered by the Swedish National Tax Board as living in Stockholm County in April 2008. Two reminders were sent out after two and four weeks respectively.

The responses were read through at the point of registry, and after the deadline for answering (July 2008), the material was transferred to an excel sheet by the main researcher. The page was divided into two parts: the description was pasted in the left column, and in the right column space was left for key phrases and indexing. Such lay-out enables quick familiarization with the material and also facilitates digital processing

of the material.[107] The data was subjected to two separate rounds of content analysis. See Figure 1.

Figure 1: Illustration of each step in the content analysis in study III and study IV



4.2.3.1 Study III, analytical process

In study III the aim was to describe experiences of negative encounters in Swedish healthcare and to investigate possible explanations for these negative encounters. The main material for study III was drawn from the responses to the two final questions in the questionnaire, describing the respondents' negative experiences of encounters with healthcare personnel, either as a patient or as a relative:

(Q.8) "Do you have experience of negative encounters as a *patient*?

- Yes/No

If yes, please provide a description of the event(s):……."

(Q.9) "Do you have experience of negative encounters as a *relative or guardian of a patient*?

- Yes/No

If yes, please provide a description of the event(s):……."

The descriptions were subjected to conventional content analysis for the purpose of identifying and categorizing descriptions, as well as underlying factors relevant to the respondents' negative experiences of healthcare encounters.[108] Conventional content analysis is used when existing research on the topic is limited and the aim of the study is to explore and describe a phenomenon or experience. This way we can gain a richer understanding of the phenomenon without imposing preconceived understandings or perceptions on the material. Instead, all categories are derived during analysis.[108]

Indexing process

The indexing process was initiated by the main researcher who read the compiled text through thoroughly. Some contextual patterns emerged quite soon, and after a few pages initial key phrases had been identified. The material was read one more time and additional key phrases, i.e. meaning-bearing units, were identified. The next step was to develop themes induced from the text by grouping similar meaning bearing units together. These groups were initially given short denominations such as "violence", "injustice", "rude" and so forth. The groups were open for modification, and when one key phrase did not fit into an already existing thematic group a new one was created. At this stage 14 thematic groups or "items" were identified. The dataset was then passed over to a second researcher who also went through the text and independently

processed the data in similar vein. The second researcher suggested amendments in terms of inclusion criteria and after negotiating back and forth a new set of 16 items was established. The researchers then jointly went through the dataset to assess consistency, completeness, and overlapping of the proposed items. During this process, supportive illustrative quotations to each item were identified. Finally, two other researchers critically revised the proposal, also looking at consistency, completeness, and overlapping of item content. The joint efforts resulted in some further modifications and finally 17 "descriptive items" could be established. These 17 items were clustered and condensed into six sub-categories, which finally generated two overarching explanatory categories.[109]

A minor statistical analysis of frequency and proportions was conducted.

4.2.3.2 *Study IV, analytical process*

In the fourth study the objective was to investigate the hypothesis that complaints of adverse events related to the encounter with healthcare personnel were underreported to Patientnämnden (PaN), and to identify barriers to filing such complaints. In addition, we also investigated if trust and experiences of encounters in healthcare were associated. The main data were drawn from two questions in the questionnaire:

(Q.6) Have you ever filed a complaint regarding a healthcare encounter at the Patients' Advisory Committee?

- Yes/No

(Q. 7) Have you had reason to file a complaint to the Patients Advisory Committee but refrained from doing so?

- Yes/No

If yes, what was your reason for not complaining?.....

The reasons stated for not filing complaints were subjected to qualitative content analysis and the results were presented in clusters. The reasons stated were, following a procedure similar to that described above (study III), first identified and classified into 17 basic (first-level) themes based on their main content. Thereafter the basic themes were clustered and condensed into a smaller set of five comprehensive second-level themes.[108],[109]

For carrying out the quantitative analysis, we used the software package Epi-Calc2000. Odds Ratios (OR) with 95% conficence intervals (CI) were calculated for the respondents' general experience of encounters in healthcare (Q4) in relation to (Q8) their personal experience of negative encounters in healthcare, as well as for the respondents' general experience of encounters in healthcare (Q4) and (Q3) their degree of trust. Lastly, we counted the respondents stating that they had had reason to file a complaint (Q6) but had refrained from doing so (Q7). See Appendix 2. The answers to questions 6 and 7 were measured in proportions with confidence intervals (CI 95%), in relation to the respondents' general experience of healthcare, and in relation to the respondents' level of trust in healthcare. When testing he "iceberg" hypothesis (that is; the hypothesis that complaints about negative encounters are under-reported) we applied the chi^2 test, with significance level 0.05.

5 SUMMARY OF RESULTS

Below follows a summary of the main findings from the four studies:

5.1 STUDY I

The aim of study I was to investigate patient's experiences of not being treated well in medical healthcare in Stockholm. We found that women had a higher complaint rate than men, and that the main reasons for reporting complaints on the encounter were experiences of rude, aggressive or arrogant behaviour, being ignored, not listened to, or not being taken seriously. For a complete list, see Table 2.

Experiences of negative encounters were in 2006 and 2007 the fourth most common reason for complaining to PaN and accounted for about 13% of all registered complaints. However, a random control of the complaints that had been categorized by staff at PaN as mainly concerning 'medical treatment' (the most common reason for filing a complaint to PaN) revealed that experiences of negative encounters (in the article referred to as "bad treatment") may be much more common. In almost one third of the complaints on medical treatment there were also complaints about negative encounters. The complaints, however, had not been registered as such since the initial claim concerned another topic.

Table 2: Categories of complaints

Complaints about bad treatment to the Patient's Advisory Committee in Stockholm, Sweden during 2006 and 2007 Complaint category	Percentage of all complaints about bad treatment
1. Rude, aggressive or arrogant behaviour	22 %
2. Being ignored, not being listened to, or being taken seriously	19 %
3. Being denied examinations or treatments	9%
4. Lack of empathy	5%
5. Lack of respect for personal integrity	5%
6. Lack of time/waiting time, stressed personnel	5%
7. Personnel not separating private issues from their professional role	1%
8. Injustice and discrimination	2%
9. Sexual harassment	1%
10. Violence and coercion	2%
11. Unspecified bad treatment	28%

Different people have different ways of interpreting situations. In our discussion we underlined that someone's perception of an occurrence and what actually happened may not always coincide. For instance, a patient may have been given sensitive information by the doctor out of earshot from others, yet may have gained the impression that others heard it. We suggest four possible perspectives on such events, based on combinations of actual bad treatment and perceived experience of

bad treatment (with 'yes' and 'no' as alternatives for each; see Figure 2). We suggest such a figure, showing the possible relations between subjective and objective interpretations of an event, as a useful tool when assessing whether a patient's experience of a negative encounter can be justified or not:

- the patient feels badly treated and the patient was badly treated (1),
- the patient feels badly treated but the patient was not badly treated (2),
- the patient does not feel badly treated but the patient was badly treated (3), and
- the patient does not feel badly treated and the patient was not badly treated (4)

Figure 2: Possible relations between perceived and actual bad treatment

		Actual bad treatment	
		YES	**NO**
Perceived experience of negative treatment	**YES**	1	2
	NO	3	4

However, since the negative health and wellbeing effects of negative experiences of healthcare encounters are present regardless of whether or not the patients in fact have been badly treated, the focus must be on reducing these experiences.

5.2 STUDY II

The aim of study II was to examine how patients perceive healthcare encounters, with a special focus on negative encounters and feeling wronged. The respondents were long-term sickness absentees.

The response rate was 58% (5 802). Of the respondents, 1 628 persons stated that they had experienced negative encounters with healthcare staff. Of this sample, 1 036 (64%) persons also reported having felt wronged by such an encounter. The most common types of experienced negative encounters were nonchalant and disrespectful behaviour by the caregiver. These two items also had the highest attributable risk of feeling wronged: "nonchalant behaviour" AR 71.1% [95% CI: 66.3-75.8] and "treated me with disrespect" AR 54.8% [95% CI: 49.8-59.8]. See Table 3. Women were found to be slightly over-represented regarding experience of negative encounters, but men more often reported feeling wronged if exposed to negative encounters. Men had higher AR for feeling wronged in relation to all types of negative encounters, though not all differences were statistically significant.

Further, the results indicate that many items associated with feeling wronged were intertwined, indicating that feeling wronged is an outcome based on several experiences of negative encounters in healthcare, either bundled together in one and the same event, or in a series of events.

With regard to our results, the discussion focuses on three main explanations to why negative encounters in healthcare occur: structural explanations, attitudes among healthcare personnel, and communication practices. Perceptions and expectations of the individual patient are also highlighted as a potentially actuating area where measures could be aimed for preventing dissatisfaction. Since different aspects of negative encounters are intertwined, we especially endorse efforts to improve communication skills, including the attitudes and official priorities communicated, as a potentially fruitful target for improving patient-caregiver interaction, and thus the experience of the encounter.

Table 3: AR with 95% CI for feeling wronged when having experienced different types of negative encounters with healthcare staff

Type of negative encounter (Number of exposed respondents)	All (n=1 628) AR% (95% CI)	Men (n=487) AR% (95% CI)	Women (n=1 141) AR% (95% CI)
Nonchalant behaviour (1 280)	71.1 (66.3-75.8)	80.1 (73.3-86.9)	68.3 (62.6-74.1)
Treated me with disrespect (1 041)	54.8 (49.8-59.8)	63.5 (56.2-70.8)	52.2 (46.0-58.3)
Did not believe me (1 042)	41.1 (36.1-46.1)	46.6 (38.1-55.1)	39.5 (33.5-45.4)
Doubted my condition (1 077)	36.8 (31.4-42.1)	42.4 (32.8-52.0)	35.1 (28.7-41.4)
Did not listen (982)	34.6 (30.2-39.0)	**44.6 (37.0-52.2)**	31.5 (26.3-36.8)
Treated me as stupid (808)	32.5 (28.6-36.4)	38.6 (31.7-45.4)	30.7 (26.1-35.3)
Was irritated/impatient (914)	31.2 (26.9-35.4)	40.3 (32.1-48.6)	28.4 (23.5-33.4)
Was too impersonal (916)	29.2 (24.9-33.4)	**39.4 (31.7-47.2)**	26.1 (21.1-31.1)
Rejected my suggestions for solutions (903)	28.4 (24.3-32.4)	**46.7 (39.0-54.4)**	22.8 (18.2-27.5)
Angry/unpleasant behaviour (706)	26.4 (23.1-29.8)	33.5 (26.1-40.8)	24.3 (20.6-28.1)
Was stressed/did not make time for me (1 075)	24.9 (19.9-29.9)	35.6 (25.8-45.4)	21.7 (15.9-27.5)
Questioned my desire/motivation to work (913)	23.9 (19.9-28.0)	25.7 (17.4-34.1)	23.4 (18.8-28.0)
Interrupted me (659)	20.3 (17.1-23.4)	**28.5 (22.2-34.8)**	17.8 (14.2-21.3)
Made unreasonably high demands (787)	15.6 (12.0-19.2)	**26.8 (19.6-34.1)**	12.2 (8.1-16.3)
Blamed me for my condition (451)	12.2 (10.0-14.4)	**18.0 (12.9-23.0)**	10.5 (8.0-12.9)
Did not let me take responsibility for myself (469)	10.7 (8.4-13.0)	**17.9 (12.1-23.7)**	8.5 (6.1-10.9)
Doubted my capacity to work (693)	9.3 (6.2-12.4)	15.8 (8.1-23.4)	7.4 (4.1-10.7)
Did not keep our agreements (418)	6.5 (4.4-8.6)	9.7 (4.4-15.0)	5.5 (3.3-7.7)
Talked in a way I could not understand (397)	4.5 (2.3-6.7)	8.0 (2.7-13.3)	3.5 (1.1-5.8)
Threatened me (116)	3.3 (2.4-4.2)	**6.1 (3.6-8.6)**	2.5 (1.6-3.4)
Harmed me physically (103)	2.1 (1.2-3.0)	**5.0 (2.5-7.6)**	1.2 (0.3-2.1)
Did not make high enough demands (117)	1.7 (1.2-2.6)	1.9 (-0.5- 4.4)	1.6 (0.7-2.5)
Sexually inappropriate behaviour (30)	0.7 (0.2-1.1)	1.4 (-0.0-2.9)	0.4 (0.0-0.8)

Adjustments have been made for age, reason for being sick-listed, and education.

Bold figures indicate significant differences between men and women.

5.3 STUDY III

Manuscript

The purpose of the present study was to gain an improved understanding of negative encounters and to describe the general population's experiences of negative encounters in healthcare. We also wanted to investigate factors possibly underlying the negative encounters.

The response rate was 62.1% (n=922); 58 % were women and 42% were men. Of the 922 persons who completed the questionnaire, 340 had enclosed comments on at least one of the questions, and substantial descriptions of negative experiences as a patient or as a relative (Q8 and Q9) had been submitted by 295 of these respondents. Frequency and proportions were calculated for the first seven questions, and the free-text descriptions for questions Q8 and Q9 were subjected to conventional content analysis.[108]

837 (92.5%) of all respondents stated that they had a very or fairly positive general experience of encounters in Swedish healthcare, while 67 (7.5%) respondents stated that they had a fairly or very negative general experience. At the same time, about one-third of the same respondents reported personal experiences of negative encounters, either as a patient or as a relative.

A gender-based difference was found. Of those with some kind of negative experience of encounters, a higher proportion were women [60.8% (CI 55.4-66.2)] than men [39.2% (CI: 33.8- 44.6)]. Negative experiences of encounters were also more common among younger respondents aged 18-49 years [59.9% (CI: 54.5-65.3)], than in the older age group aged 50-89 years [40.1% (CI: 34.7-44.5)]. The differences were statistically significant.

The analysis showed that descriptions of negative encounters (items) entailed poor availability, being denied medical examination and/or treatment, inadequate routines, inadequate information, disbelief, and unpleasant behaviour. For a complete list, see Table 4. The descriptive items were divided into six subcategories which could further be divided into two categories yielding overarching explanatory factors for the expressed behaviour: structure and allocation of healthcare, and the staff's attitudes and professional practice. See Table 4.

These explanatory factors, although they may to some extent interact, indicate what kind of preventive measures might be proposed in order to avoid negative encounters depending on what level they stem from. For example, to make healthcare staff reflect

on their own behaviour and ethical standpoint, or to focus on communication and improving communication skills, may improve the patient-caregiver relation and raise patient satisfaction. Structurally determined experiences of negative encounters may on the other hand be prevented on an organizational level. For example, working in a substandard environment may cause the caregiver to feel stress or frustration, which may be reflected in their attitudes and behaviour. Many of these predicted negative events could be prevented by improving the organization of the workplace or changes in the allocation of resources.

Table 4: Descriptive items, subcategories, and comprehensive categories

Descriptive item	Subcategory	Category
1. Availability 2. Being denied medical examination and/or treatment	A. Supply	
3. Inadequate routines 4. Inadequate continuity 5. Inadequate co-ordination	B. Organization	**Structure and allocation of healthcare (A, B, C)**
6. Inadequate information from healthcare	C. Information	
7. Lack of professional conduct 8. Lack of medical skills	D. Professionalism	
9. Did not listen 10. Disbelief 11. Lack of interest/commitment 12. Lack of empathy/ understanding	E. Defective attention	**The staff's attitudes and professional practice (C, D, E, F)**
13. Discrimination 14. Unpleasant behavior 15. Sexually undue behavior 16. Physical and verbal assault 17. Disrespect for a patient's personal sphere	F. Disrespectful behaviour	

Letters in parenthesis allude to the subcategories included in the present category. The items overlap to some extent, due to purposive categorisation.

5.4 STUDY IV

In this paper the objective was to investigate the hypothesis that adverse events related to the encounter with healthcare personnel are underreported to Patientnämnden (PaN), and to identify barriers to filing such complaints. In addition, we investigated whether trust in and experiences of healthcare are related.

The response rate to the questionnaire was 62% (n=922). We found that patients often chose not to file a complaint even when they felt they had legitimate reasons to do so, and that the main barriers to filing complaints were that the patients did not have the strength to make them, did not know where to turn, or did not find it worthwhile since they did not believe it would make a difference. For a complete list, see Table 5.

Official complaints to PaN had been filed by 2,7% (n=23, CI: 1.7-3.7) of the respondents, but as many as 18.5% (n=159,CI: 15.9-21.1) of the respondents expressed in the questionnaire that they had indeed had legitimate reasons to complain, but had chosen to abstain from filing a formal complaint ($p<0.001$). This is a considerable discrepancy (1:7), and the result supports our hypothesis that complaints on negative encounters to PaN are underreported. A possible conclusion is that we probably only see the "tip of an iceberg" in official reports.

We also found that a negative general experience of healthcare (Q4) seems to have a negative effect on the patient's general trust (Q5) in healthcare. Respondents with a general negative experience of Swedish healthcare also had a higher degree of under-reporting adverse events than respondents with a general positive experience.

The study illuminates, in detail, barriers to filing complaints to PaN, and the findings should be useful for enabling healthcare staff to work actively to provide a supportive environment for patients in the case of adverse events. It is also recommended that both PaN and other actors in the healthcare system increase their efforts to provide patients with accurate information as well as create a supportive and safe system for handling complaints.

Table 5: Reasons for not filing official complaints to Patientnämnden

First level themes	Second-level themes
I did not have the strength (n=39)	
I was afraid of the consequences (n=8)	
I do not like to complain (n=3)	Weakness
I did not want to relive the trauma (n=1)	
I was not the closest relative (n=1)	
It makes no difference anyway (n=17)	
I had other priorities (n=14)	
It was too difficult (n=13)	Futility
I did not have time to do it (n=8)	
The damage was already done (n=5)	
I did not know where to turn (n=18)	
Lack of knowledge. I did not know/think I had that option (n=4)	Lack of knowledge
I did not complain out of consideration of the accused person (n=3)	Mercifulness
I did not complain due to collegial relations (n=2)	
I complained directly at the hospital (n=4)	Other action taken
No reason stated (n=19)	

5.5 ERRATA

5.5.1.1 *Study I*

The percentages presented in Table 1 in the published paper were recalculated during revision of the submitted manuscript. As the new percentages were reported, the order of the categories were not updated, which is why categories 7-10 have not been hierarchically ordered. See Table 2 in the thesis.

5.5.1.2 *Study II*

In the published paper (page 231) we account for 1 621 respondents with both positive and negative (mixed) experiences of encounters, and 164 with only negative experiences. These two groups were merged in the subsequent analysis. However, we happened to leave out a description of how the merged group was first adjusted in the sense that respondents who had not completed all relevant questions were excluded. The exclusion resulted in an internal drop-out rate of 8.9% (n=157). The correct number of included respondents in the group with negative experiences is 1628 (as can be seen in Table 1 in the published paper).

5.5.1.3 *Study IV*

Unfortunately, the published paper contains two inaccuracies. One is more incriminating (nb. 1) since it refers to a different proportion (4.8%) than the one intended and could therefore be misleading. However, the analysis and following discussion are based on a calculation of the correct proportion (7.8%), wherefore the inferences are still valid. The other error is a misprint and makes no substantial difference for the interpretation or discussion.

1) Page 1. Abstract (results): "The degree of underreporting was greater among patients with a general negative experience of healthcare (37.3% CI: 31.9-42.7) compared with those with a general positive experience **(4.8% CI: 2.4-7.2).**
   Errata: The proportion "**4.8% CI: 2.4-7.2"** has been confused with the correct proportion of 7.8 (5.6-10); see Table 1 page 3 in the published paper.

2) Page 2. Material and methods: "Of the sample of 1500, 16 questionnaires were returned due to death or unknown address; altogether **992** participants (62.1%) returned a completed questionnaire…"
   Errata: The correct number is 922. See page 1 of the published paper.

6 DISCUSSION

In this chapter I intend to discuss what we have learned about the experience of negative encounters in healthcare, and to some extent how they can be prevented. The discussion is divided into two sections; first I will present some relevant methodological considerations, followed by an account of possible interpretations of the key findings in the studies and what practical conclusions to draw from them.

6.1 METHODOLOGICAL CONSIDERATIONS

This thesis combines qualitative and quantitative approaches, and the focus has mainly been on descriptive analysis. By combination of methods and access to fairly large sets of data we could increase the chance of obtaining variety in the answers and at the same time, to some extent, be able to describe prevalence and certain relevant associations, thus providing a comprehensive view of the phenomenon of experiences of negative encounters in healthcare.

6.1.1 Validity and reliability

Validity concerns the consistency between what we claim to investigate and what we actually investigate. To achieve this we need to ensure reliability in the analysis; that is, a systematically reliable procedure.[110] The requirements for validity differ somewhat in quantitative and qualitative studies, but both types require "internal validity". In quantitative studies the internal validity relates primarily to "face validity" which is that the process and quality of the measurement are empirically based and also appear adequate to an objective observer. Validity in qualitative research, however, includes the whole process of determining sample, the collection of data, the analysis and choice of theoretical framework. Internal validity is a way to ensure credibility and requires the researchers to clearly describe each step of the method, as well as potential dropout factors.[110],[111] To ensure internal validity in our studies, we have emphasized clear and detailed descriptions of methods and analysis in the papers, and in study II the questions of the survey were also developed based on input from several preceding studies. This issue will be further explored below, as will potential biases and drop-out factors.

"Criterion validity" indicate that the results are consistent with results from studies by others or simultaneous measurements using another method or technique. Criterion validity is generally not considered in qualitative research,[110] but can actually be

applied to some parts of our studies. The studies had different methodological designs so the findings are not comparable in all aspects, but the main results in studies I-III; i.e. the descriptions of what a negative encounter entails, are consistent through all studies included and also harmonize well with previous knowledge about healthcare encounters that was accounted for in the background section of the thesis. Independently of whether the respondents were provided with fixed alternatives of negative encounters, or whether they described the event in their own words, common denominators have been constant, which could be interpreted as a sign of criterion validity.

6.1.2 Reproducibility

Reproducibility means that all aspects of a study can be replicated and that the analysis would yield the same (sufficiently similar) results. This requires a systematically reliable procedure as well as a transparent study design with each step of the data collection and analysis specified. In quantitative research, where the sampling is systematized and standardized procedures (such as established laboratory techniques or standardized questions) and measurements are applied, this should generally not be a problem.[112]

The questions and the statistical analysis in study II have been carefully described, and since the survey concerns a specific target population (long-term sick-listed persons), and has a structured design with fixed questions and response options, there should be no barrier to reproducibility.

Content analysis, however, cannot be fully detached from the researcher's subjective interpretation, which makes reproducibility harder to obtain. Therefore, the analyses in study I, III and IV were conducted by two or more researchers jointly to ensure a certain level of confirmability,[110] and each step in the study process has been carefully described. Given this transparency, it should be possible for an observer to grasp the conditions for the analysis, and to reproduce the study with the same or similar results.

6.1.3 Generalizability

Three of the studies included are based on surveys. Surveys are generally used to answer questions regarding *how, when, where,* and *what*, and are suitable for studies with a large sample population. The strength of surveys normally include their convenience, accuracy and representativity. Although some of the analyses of the

studies were qualitative, their being based on questionnaires actualizes the question of generalizability.[113, 114]

In study I, we performed a purposive sampling by using an existing registry where all available complaints of negative encounters in healthcare were included (n=1 248). We cannot define the sample population in more detail than with reference to their common experience of negative healthcare encounters (and their reporting them to PaN in Stockholm county). This generally means that we need to be very cautious in generalizing the results on the general population. However, since the primary aim was to find and define different categories of negative encounters, and not their statistical distribution, the question of generalizability is of minor importance.

Study II concerns long-term sick-listed persons, arguably a group distinguishable from the general population in that on average they have poorer health. Therefore the results may not be generalizable to the general population but only to long-term sick-listed individuals. The sampling strategy was proportional with regards to gender, and the number of participants high (n=5 802). 1 628 respondents were covered by the inclusion criteria (having experiences of negative encounters with healthcare personnel) and were included in our study. This sub-group was large enough to allow statistical analysis. The drop-out rate was relatively high, but considering that the sample included several individuals with severe diseases, it may be argued that the response rate is acceptable.[37] However, I will discuss alternative views on participation of individuals with low health standard more thoroughly below (section 6.1.3.1.2: "Patients with a low health standard").

The results in studies III-IV are derived from a systematically randomized fractional sample. Assuming that the sampling process has been conducted properly, the results we obtain from the sample should be more or less representative of the general population in Stockholm. The sample size for the survey based studies III and IV were set to n=1 500. This number was chosen because it was estimated to be sufficient to yield statistically significant results even with a low response rate. However, the questions of generalizability and representativeness are not a primary concern in these studies. Our purpose has primarily been to find and describe types of negative encounters or barriers to filing complaints, not their prevalence or distribution. It is, however, problematic for a qualitative study if some results (types of encounter in the present instance) never occur in the material, due to groups with unique experiences not participating. This would be the case, for example, if complaints of racism were absent

from the material due to no participants with different ethnic backgrounds participating in the study (however, regarding this specific example, we did manage to identify such encounters).

Are the findings generalizable to a broader population, for example to the population of Sweden? As mentioned earlier, due to the specific target population the findings of study II are probably not. Study I contains complaints about healthcare encounters experienced in Stockholm County by residents of Stockholm County. However, the findings on different types of complaint are similar to other studies of complaints on encounters, for example to Patientnämnden in Halland[41] and northern Sweden[43], which speaks in favour of their being representative also experiences of a broader population. Studies III and IV, although conducted in Stockholm County, were not explicitly confined to experiences gained in Stockholm County, nor did we exclude descriptions of experiences gained elsewhere in Sweden. Since the Swedish healthcare system is more or less similarly organized all over the country, it might be reasonable to assume that similar experiences are likely to appear independently of whether you are in Stockholm or, say, in Umeå.

What people perceive as negative encounters is probably fairly similar in many countries, but factors such as healthcare systems (private or tax-funded , developed or under-developed), culture, values, perceptions of people's right to self-determination and the like are likely to affect people's expectations of the healthcare system and their perception of the healthcare encounter. Therefore, great caution must be exercised when attempting to generalize many of the findings in our studies to other countries.

6.1.3.1 *Drop out*

We know from earlier studies that men, younger persons, immigrants, and persons with less education are under-represented as participants in surveys,[76] and it is reasonable to assume that the same excluding bias affects all our studies to some extent. In our studies too, for example, there is an under-representation of men and younger persons as participants. An educated guess is that immigrants as well as persons with less education may also have participated to a lesser extent. I have not been able to investigate such factors more profoundly within this thesis. However, I will comment more in detail below on two potential drop-out factors that may have special relevance to studies of healthcare encounters: language and health status.

6.1.3.1.1 Language

One issue which possibly biased the studies was that the studies were exclusively conducted in Swedish. It is difficult to quantify the effect of this language factor, but it is reasonable to assume that it affects all four studies. This is problematic if it means that participants who do not master the Swedish language are exposed to structural exclusion.

However, due to resource limitations, a questionnaire can only be distributed in a limited number of languages and there is no way of ensuring that the languages chosen will cover the needs of the whole sample population. This is the reality for everyone who works with surveys, and the problem is more or less accepted as valid losses.[76] As already noted, such problem is also of less importance to qualitative studies than to quantitative ones.

Exclusion due to language difficulties is primarily pertinent in the survey-based studies, but probably also affects complaints to PaN about negative encounters. For example, for a non-native Swedish speaker it may be particularly difficult to find information about where to file complaints, especially if written information in hospitals and other healthcare facilities is mostly given in Swedish. Supposing that the person still manages to find the information, then another problem arises: that of registering the complaint. If there are no interpreters available, the complaint may not be translated, in which case it will not be registered.

Efforts have been made to reach and support these patients, and information in a variety of languages is now to be found, for example, on the PaN website.

6.1.3.1.2 Patients with a low health standard

It has also been claimed that patients with a heavy disease burden have a lower response rate in surveys compared to the general population.[115] This is a logical consequence of being weakened by disease, and may result in an under-representation of this population and their specific complaints. The same reasoning is probably also applicable when it comes to those who are worse off health-wise, for instance patients in palliative care or patients with multiple or chronic diseases.

One may, however, question whether this also holds good regarding surveys that have to do with negative encounters in healthcare. Patients with severe diseases often have a higher degree of accumulated healthcare experiences and, as argued for in study II, have accordingly been exposed to a higher risk of being negatively encountered.

Could it not be that these patients are actually the ones who are particularly keen on participating? If you have experiences of negative encounters, is it not likely that you are more motivated to participate in a survey about negative encounters compared to those without such experiences?

6.1.3.1.2.1 RECALL BIAS

A related issue concerns recall bias. Briefly; people react to and remember negative impressions more clearly than those they perceive as being positive; and contributes more strongly to the final impression than positive impressions and experiences does.[116] This means that there should be a possible risk of a proportional over-reporting of negative events in comparison to positive events in surveys about healthcare encounters.

It has been argued that being attuned to bad/ negative events rather than good/positive events is a general principle or law of psychological phenomena.[117] This view is based on a presumed evolutionary requirement for organisms to be attentive to bad and presumably dangerous events in order to survive and successfully pass on their genes. The researchers of a thorough review of the literature about the issue concludes that there are hardly any exceptions to this principle, and add: "From our perspective, it is evolutionary adaptive for bad to be stronger than good".[117] This might explain which encounters the respondents remember and choose to describe. Most people expect to be treated nicely when they visit healthcare and do not reflect on the encounter unless something unexpected happened. This effect, however, has no relevant impact on the qualitative studies, although it might have helped the respondents to provide us with interesting data.

6.1.4 Other methodological concerns

Apart from general considerations regarding validity, reproducibility, and generalizability, there are also a few other aspects of methodological choices that I wish to clarify. In the following section I will first motivate our choice of sample populations and comment on our lack of focus on general background factors. I will then briefly comment on specific considerations that are relevant to the separate studies that I have not addressed in the above sections.

6.1.4.1 *Gender, education, country of birth, social status and health status*

The studies included in the thesis do not thoroughly analyse many of the known confounding factors such as gender, education, country of birth, social status, or health status. We claim such analysis would steer the focus away from the phenomenon of experienced negative encounters. Such analyses are important as a means to promote equal and adapted healthcare distribution and to promote patient safety, but require theoretical explanation-models that go beyond the scope of the thesis. We strongly recommend further complementary research on these factors in order to ensure a highly qualitative healthcare.

6.1.4.2 *Excluded background question*

Another methodological consideration relevant to studies III and IV is the issue of constructing relevant questions for the studies' purposes. In order to design a successful questionnaire it is essential to carefully consider *why* each question should be included and *how* it is intended to be operationalized.[112, 118]

When developing the questionnaire serving as basis for study III and IV, we were careful to formulate, test, and re-formulate all the queries carefully in order to create clear and understandable questions, and limit all risks of misinterpretation. We also included background questions regarding gender, age and previous experience of having worked within healthcare, in hope of seeing if there was a difference in how respondents with professional experiences from the healthcare perceived encounters in healthcare, compared with respondents without such professional background. However, we did not anticipate the broad range of work experience within healthcare that was stated, and since we had not developed any precise definition of the professions to be included in the analysis, we were eventually forced to exclude this question from the analysis. (See appendix 2: Background questions) The lesson learned was to enlarge more carefully on how to operationalize the background variables to ensure validity and reliability,[113] but also to be careful to clearly motivate each question.

6.1.5 Studies I-IV, specific methodological considerations

6.1.5.1 *Study 1:*

The material analysed in Study I had already undergone categorization with reference to the main content of the complaint conducted by Patientnämnden before we took part of the material. Hence, there is a risk of complaints about negative encounters having "disappeared" during this process if they were deemed subordinate to another complaint. As with the case of drop-out factors, we believe that this does not affect the types of encounter occurring in the material. However, we admit a possible risk of the proportional distribution of the complaints being affected. For instance, complaints about being denied a requested treatment or examination could theoretically have been categorized as a complaint regarding "medical treatment"

6.1.5.2 *Study III-IV:*

In-depth interviews or focus group discussions are generally considered to be adequate methods for generating qualitative accounts of experiences. However, since we were not looking to convey complex social relationships or interaction,[113] but rather "what", "where", "when", and "how",[118] i.e. straightforward descriptions, a large sample, and maximal variation, we concluded that a semi-structured questionnaire would be a proper instrument to gather information about our research interest. In surveys you lose the opportunity to gain profound understanding, but instead receive input from a much larger sample of respondents than would ever be possible with the other options. Also, in study IV we wanted to find out how many of the respondents who had experience of lodging complaints with PaN, and also to measure trust in and general experience of Swedish healthcare – and to answer these questions you need a large sample.

6.1.6 Ethical considerations

6.1.6.1 *Covering letters*

The two questionnaires had, in accordance with the formal requirements for surveys, a covering letter attached describing the aim and scope of the study. The covering letters contained information about the participation being confidential, voluntary, and that respondents were free to withdraw from participation without having to give a reason for doing so. Information about how to get into contact with the researchers was enclosed. See appendices 1 and 2.

6.1.6.2 *On asking potentially harmful questions*

There are a few specific aspects that the researcher needs to consider when sending out a survey about potentially sensitive issues. The first is that it might be something the respondent is ashamed of, which may cause them not to answer (internal drop-out).[115,119] It may also, in some cases, cause them to modify their descriptions of the actual experience (social desirability bias).[115]

It is also crucial to carefully consider whether your research can cause harm to the participant. Could asking questions about negative encounters possibly have any negative consequences, of such a kind as to provoke discomfort by reviving traumas and unpleasant memories? Will the presumed results be worth the risk of causing the participant harm in any way? It is, furthermore, advisable to be prepared to take responsibility for the respondent's psychological or emotional reaction and to offer support if needed.

We asked ourselves these questions before sending out the questionnaire (Studies II and III) but concluded it to be sufficient to provide the respondents with information about how to contact the research team. Should extra need of support be needed, this would be handled ad hoc. The decision not to plan for potential supportive follow-up was based on the judgment that since the aim and intent of the study had been clearly described in the covering letter, the respondents could choose to neglect the questionnaire as soon as they realized that they might find it upsetting, or send in an empty questionnaire. The latter alternative was exercised by 88 persons.

6.2 SUMMARIZING DISCUSSION OF MAIN FINDINGS

So what have we learned in these studies? First of all, our suspicion that negative experiences of encounters in Swedish healthcare might be more widespread than what is seen in public reports seems to have been justified. However, this finding might be considered as not very surprising, given the fact that a general tendency of underreporting of complaints and adverse events is well-known from previous research.[120–123] Nonetheless, looking at the details of the results, we will see that there is plenty more to be learned.

6.2.1 Experiences of negative encounters in healthcare

The commonness of negative experiences of encounters in healthcare was first noted during Study I, where we made a complementary snapshot review of complaints on medical treatment and found that about one-third of them also contained complaints about a negative encounter. In Study II, 28% of the respondents stated that they had experiences of negative encounters. Finally, in the questionnaire analysed in papers III and IV, 37% of the respondents were found to have negative experiences. Studies III and IV, however, differed notably from Studies I and II in their design, since they included accounts of experiences gained both in the role as patient and in the role as a relative, but also because the questionnaire did not have a time restriction as to when the experience was gained. These structural differences, and the fact that the questionnaire clearly addressed the topic of negative encounters (with a potential risk of selection bias), may explain the somewhat higher proportion of negative experiences found in these studies.

6.2.2 Descriptions of the negative encounter

There is consistency between the studies about what the respondents perceive as a negative encounter. Complaints on arrogant, nonchalant, and disrespectful behaviour were frequently reported as reasons for feeling negatively encountered (and also wronged). These terms are all more or less generic, but paint a picture of a patient-caregiver relation that does not live up to basic social requirements such as treating each other with respect and consideration. Other complaints concern not being listened to, being ignored, or not being believed. Such experiences can be interpreted rather as a question of being deprived of your right to be involved in decisions concerning your own treatment, and being hindered in asserting your right to self-determination.

Availability, stressed personnel, poor coordination, and inadequate routines point at experiences gained through exposure to what may be a substandard healthcare service, yet they are often perceived as a matter of being negatively encountered by a specific individual. Such experiences may have to do with patients' expectations on the healthcare service. When a caregiver is unable to live up to the patient's expectations, the patient may hold that person responsible, although at times it may rather be a matter of organizational flaws or rationing decisions. Experiences of violence, coercion, sexually undue behaviour, discrimination, and verbal assaults are also present in all included studies, although not very frequently. The art and the occurrence of the types of experiences of encounters found in our studies harmonize well with previous knowledge about experiences of negative encounters.[5,10,37,41,44,124]

Another take-home message is that patients do not necessarily separate between how they are treated by medical staff (the encounter) and the medical treatment they receive. Rather, to many they are two sides of the same coin. It should not come as a surprise that those seeking care expect a certain standard of competence and professionalism regarding both medical treatment and how they are treated as persons. A person who seeks care ultimately does so in hope of feeling better afterwards and in "feeling better", it is reasonable to assume that the patient includes both physical and mental comfort since both are essential to wellbeing. That many patients do not differentiate between the encounter and the medical treatment is a strong indication that the quality of the encounter needs to be prioritized in healthcare.

6.2.3 Underlying causes for experiences of negative encounters: attitudes and behavior, or structure?

An interpretation of the findings is that negative experiences of encounters can, on a basic level, be explained by the staff's attitudes and behaviour (professional practice) or by how the healthcare service is structured. These factors may also interact. Personal attitudes and behaviour may not always correspond with official values in the healthcare system, and might affect how caregivers interact with certain patients. They may also be caused by a lack of professionalism, where the caregivers fail to adjust their expression of personal emotions or behaviour to the requirements of their professional role, thus failing to meet the expectations of the patients.

Structurally caused experiences of negative encounters, however, often relate to the patient perceiving the caregiver as stressed, unavailable, or unwilling to agree to a

requested examination or treatment. The behaviour of healthcare personnel is highly influenced by organizational and structural restrictions as well as official priority settings. Working in a sub-standard environment, with harsh rationing restrictions, may be frustrating for the healthcare staff, who may not be able to hide their discontent, or even project their frustration on the patients.

6.2.3.1 *Communication*

Many of the complaints on negative encounters would probably never have been filed if there had been a better communication. This statement is probably applicable to many of the negative experiences, but concerns, in particular, complaints regarding poor information, not feeling listened to, being interrupted, or complaints against caregivers who have not kept agreements. Communication practices can be affected by structural aspects, such as allocation of time for each patient, or personal attitudes or beliefs (for example, people may have different ideas about how to address elders), but are also in many cases caused by poor communication skills by the caregiver. Good communication skills include the capability to listen and to summarize, to inform, to include, and discuss with the patient on a level suitable for that specific individual,[125] and is associated with better safety and positive health outcomes.[48–53] Poor communication is associated with lower adherence to treatment, lower levels of patient satisfaction, higher complaint rates, and an increased risk of exposure to medical malpractice and adverse events,[48–52,54] factors that may lead to poorer health outcomes, and put patient safety in danger.

Communication has been proposed as important for improvement of the healthcare encounter and healthcare service in all four included studies. In study I communication was proposed as a means for the caregiver to understand how the patient perceives the encounter, since it enables adjustment to the patient's needs. In study II and III we discuss that improving the communication skills among healthcare staff would be a potentially effective way to prevent both structurally determined negative experiences of encounters and negative experiences of encounters affected by the caregiver's attitudes and behaviour. The findings in study IV indicate the importance of a well-functioning communication as a way to identify barriers to report complaints and to better support and reach patients who need help to lodge complaints to Patientnämnden.

6.2.4 Effects of the encounter

Yet another insight is that the impact of experienced negative encounters can be meaningfully measured. In previous research, we have learned about associations between experiences of encounters and different types of health outcomes.[58–63] In study II we were able to ourselves see associations between the sick-listed persons' experience of negative encounters and the emotional outcome of *feeling wronged*. We also found that a combination of accumulated negative experiences may increase the perception of having been wronged. Furthermore, a related study (based on the same survey but not included in this thesis) showed that negative encounters and feeling wronged also have an impact on the respondents' perceptions of having been hindered or supported in their return to work (RTW) after having been on sick-leave.[11] Positive encounters and feeling respected significantly made the respondents feel supported, while experiences of negative encounters and having felt wronged were considered to have a hindering effect on their ability to return to work.[11]

These are but a few examples of measurable impacts of negative and positive experiences of healthcare encounters, and we strongly suggest the field to be further explored. For example, it would be interesting to try to estimate the actual impact of experiences of encounters and RTW by comparing the results with existing registers of these respondents' sick-leave length.

6.2.4.1 *On feeling wronged*

In study II 64% of the participants who had negative experiences of healthcare encounters also claimed to have felt wronged. This is indeed a rather high number, and may to some extent be explained by the fact that the respondents arguably belong to a vulnerable patient group with severe medical conditions.[126] According to the respondents, feeling wronged was often preceded by nonchalant behaviour, having felt disrespected, not having been believed, or that the caregiver had doubted the patient's condition. Men were found more liable to feel wronged if exposed to negative encounters than women.

However, these results give no indication as to *why* such large proportion of the respondents felt wronged. One possible suggestion could be that patients actually are worse encountered today. Reorganizations and constraints on the healthcare system may have hampered the space for individualized care in many public healthcare

settings, with little room for prioritizing a pleasant encounter. Another could be that patients of today object more to being negatively encountered than was the case some years ago. This may be due to changes in the healthcare system where the aim for patient centeredness has steered the patient towards a more client-oriented status, but may also have to do with increased access to information and knowledge about patient rights. This theory may partly explain why younger persons report negative encounters more often than older persons. A third potential reason could be that the use of the term wronged has increased simply because the connotation of the term has expanded. The answer, yet to be found, may include a mixture of them all.

6.2.5 Barriers to filing complaints on negative encounters

Study IV deviates from the others since it does not focus on types of negative encounters, but instead on how people act after having been exposed to them. We found a considerable discrepancy between the number of respondents claiming to have had reasons to file an official complaint of a negative encounter with Patientnämnden (18.5%) and the number stating that they had actually done so (2.7%). These numbers indicate that such complaints, at least to Patientnämnden, are largely under-reported.

The main obstacles to filing complaints were that the respondent, at the time, did not have the strength to do it, did not think it would make a difference anyway, or that they did not know where to turn.

Reasons that are connected to "lack of knowledge" (Second-level themes, see Table 5) may indicate a lack of information, reasons connected to "Weakness" could be interpreted as a sign of insufficient support, and reasons connected to a belief of it to be futile may in its turn possibly be taken as a sign of low trust in the healthcare system. These responses illuminate the importance of a supportive healthcare system that provides the patients with information as well as support in lodging complaints. Complaints about adverse events are, after all, an important source of information, germane to the improvement of everyday activity.

6.2.6 Age and gender

The findings that younger persons had more negative experiences of encounters than older persons, and that women had more negative experiences than men were consistent through all the studies included. These findings are also consistent with results in for example Norway,[36] Germany,[64] and Sweden.[10],[15],[37],[69]

Our studies offer no explanation as to why younger persons feel less well encountered in healthcare. Up-to-date studies by others are also few and far between, and do not propose any relevant explanations to this trend.

More is written about gender differences. Although we did not set out to study gender differences, the findings of our studies tally closely with previous knowledge about women's more extensive experiences of negative encounters in healthcare compared to men.[42–44,65,67] Does this mean that we know that women are actually worse treated? Some researchers question such interpretations and, without impugning the validity of these findings, I also believe that it may be of interest to discuss alternative approaches. As argued in study I, what our studies show is not in fact that women are *subjected to* worse encounters but that they *perceive* themselves as subjected to worse encounters. A similar interpretation is presented by Pukk et al.,[69] namely that women might have a lower threshold for acceptance of negative encounters and file complaints for "less" than men do. In relation to the findings in Study II, where we found that women reported more experiences of negative encounters than men, and that men reported significantly higher levels of feeling wronged if being negatively encountered than women, this interpretation gains some support. If it is true that women are more negatively encountered than men, why then do a higher proportion of the men feel wronged, which on an emotional scale represents a stronger negative feeling than, for example, not feeling listened to (item of negative encounter)? Possible explanations may be related to traditional gender structures, where women conventionally have had lower status than men, and that this makes them perceive encounters differently.[67] For example, does the fact that men are more prone to feel wronged once they are not encountered well have anything to do with males having higher expectations of being positively encountered?[127]

Women's lower status may partly explain that they are in fact more poorly treated than men, but it could also mean that women become more receptive, or sensitive, to not being encountered well, being reluctant to let discriminatory traditions repeat themselves. This would be one possible explanation as to why a larger proportion of women report experiences of negative encounters. Women's lower expectations of the encounter may also explain why they are less likely to feel wronged by it – it doesn't come as a great surprise. Men, on the other hand, may be less sensitive to negative behaviour since, expecting as they do, to be treated well, they tend not to interpret the encounters negatively. On the other hand, when it becomes obvious to

them that the encounter is negative, they tend to react more strongly to the transgression by more frequently feeling wronged.

Another view could be that men hesitate to complain unless they consider the event as truly severe. This behaviour may also be determined by gender roles, where the male is expected to be confident, strong, and to not show vulnerability.

Our findings offer no clear guidance, but we cannot exclude that the reason why women report more experiences of negative encounters could be that they, for different reasons, have a lower complaint threshold.

6.3 ENCOUNTERS IN HEALTHCARE – WHY ARE THEY SO IMPORTANT?

In any informal meeting between individuals a certain level of politeness, truthfulness, caring, and respect is expected. In a healthcare setting there are further requirements and expectations. One might think that a healthcare system which successfully treats and prevents injuries, diseases, and other medical conditions would be considered to fulfil its purpose. So why this focus on healthcare staff behaving respectfully and pleasantly? Part of the explanation might be found in the perception of professionalism. An important aspect of professionalism in healthcare concerns mutual expectations of the patient–caregiver relation. The parties entering into a doctor-patient relationship make a special sort of social contract based on the patient's right to proper information regarding their diagnosis, prognosis, and treatment, while the caregiver is entitled to relevant information from the patient. Beauchamp and Childress refer to this obligation as veracity and claim that adherence to the rule of veracity fosters trust, essential in all healthcare relations.[128]

The relation between caregiver and patient is also special due to the often vulnerable situation of the patient and the degree of intimacy which requires the caregiver to act in a respectful manner. A healthcare consultation often involves a certain level of nakedness and physical contact, as well as a dialogue regarding private and potentially sensitive issues; a way of interacting that is normally reserved for spouses or partners and that requires a high level of trust, an important aspect of which is to also guarantee confidentiality. Trust is essential in healthcare for many reasons, and the building of trust is essential to patient safety. If patients do not have confidence in the caregiver, they might not give the caregiver all information needed for correct diagnosis.[14] A low

level of trust may affect healthcare-seeking behaviour by causing delays or, at worst, causing the patient not to seek care at all.

So this gives us two preliminary answers to why encounters in healthcare are important: the positive encounter is an important aspect of professionalism in healthcare and since patients are placed in an intimate situation when in a vulnerable condition (which is to say that healthcare encounters are particularly sensitive). It is therefore important that patients feel that they can trust the healthcare staff.

6.3.1 Encounters and perceptions of encounters

Before we proceed to discuss in further detail the reasons why healthcare encounters matter, I would like to stress that what happens in such an encounter and how the encounter is perceived by the patient or the caregiver are not always the same thing.[129] In study I this is demonstrated in a model showing four theoretical ways of perceiving the healthcare encounter with regard to whether the complaint can be objectively or subjectively justified (See Figure 2). As the model illustrates, a neutral observer would probably not label all complaints as valid, so arguably the question remains: why should we care about the *perceptions* of healthcare encounters? As already mentioned, trust is a relevant aspect of healthcare encounters. There is no intrinsic connection between trustworthiness and trust in the sense of trustworthy behaviour by one party guaranteeing the confidence of the other party.[130] While a reasonable behaviour by healthcare staff certainly is relevant to trust, it does not settle the issue. Whether an individual feels that she can trust another depends on perceptions and interpretations made by that individual. Therefore the patient's subjective experiences are highly relevant to that patient's ability to trust the healthcare system and the individuals who represents it.[131]

6.3.2 The ethics of healthcare encounters

Let us now take a more systematic look at the ethically relevant aspects of experiences of encounters in healthcare. I will use the four bioethical principles propounded in the influential book *Principles of biomedical ethics* by Beauchamp and Childress as tools for analysis: beneficence, non-maleficence, justice, and respect for autonomy.[96] Although there are other ways of analysing the moral territory of healthcare, these principles have become increasingly predominant as healthcare principles, and are

often advocated by practitioners as being both basic and useful in understanding the ethical problems in healthcare.

6.3.2.1 *Beneficence and non-maleficence*

The principle not to harm (non-maleficence) provides a strong argument for not exposing the patient to negative encounters, while the principle to do good (beneficence) provides a strong argument in favor of exposing the patient to positive experiences of encounters. This conclusion is based on the empirical findings that positive encounters seem to generate positive effects and negative experiences of encounters adverse effects with regards to the patients' health, wellbeing, and self-assessed ability to return to work (RTW). Since the raison d'être of the healthcare system is the promotion of health and wellbeing, there is little reason to doubt that positive encounters are instrumentally valuable in healthcare, while negative encounters are correspondingly undesirable.

It is hard to find arguments in favor of negative encounters in healthcare. If such encounters can be justified at all, their justification would have to rely on the premise that the consequences would otherwise be worse for the patient. In other words, it is imaginable that a negative encounter may on some rare occasions be a means to a better end than what would otherwise occur. However, this would still not ascribe a positive value to the behaviour underlying the experience of the negative encounter, but to its effects.

The argumentation so far is entirely consequentialist. It should therefore be asked if negative encounters also have a negative intrinsic value, or if their negative value stems entirely from their consequences. While beneficence is normally understood as a purely consequentialist principle, non-maleficence can be understood in both consequentialist and deontological terms. The deontological aspects of non-maleficence involve avoiding actions that are bad in themselves. Thus, not to harm someone may be understood as avoiding treating someone with disrespect and avoiding to disrespect that person's rights. This standpoint involves respect for autonomy, and giving every individual a fair treatment without being discriminated against. I will return to this later in the discussion.

Before going any further, it is also worth noting that someone may in fact do harm while intending to do good. Events perceived as negative encounters may be the consequences of caregivers' unsuccessful attempts to do good to the patient. There are,

for instance, cases where patients have complained about excessive care or that caregivers in their attempt to provide good care have taken a patronizing approach, with the consequence that the patient has felt degraded, treated like a child, or humiliated.

6.3.2.2 *Justice*

As noted above, one way in which negative encounters may be bad in themselves is that they may be unfair. For instance, negative encounters due to acts of discrimination or segregation are obviously problematic from the point of view of justice and fairness (at least if discrimination is understood as being illegitimately being treated worse than others or worse than one could reasonably expect to be) . One may also interpret complaints from patients who have been denied examinations or treatments they desire or feel entitled to as founded on the their perception of fairness. They may, of course, be wrong about this. Refusals to offer examinations or treatments are generally based on medical grounds or, for instance in cases with extremely expensive treatments, due to limited resources. Paradoxical as it may seem, this means that such decisions *not* to offer examinations or treatments may actually be justified on equity grounds. Nonetheless, some complaints may be grounded in actual injustices and many are most likely grounded in perceived ones.

6.3.2.3 *Respect for Autonomy*

This principle states decision-capable patients' right to self-determination. A positive encounter is a prerequisite of good communication, which in turn is a precondition for making the patient capable of participation and self-determination. Not to be listened to is among the most common complaints about encounters in the healthcare system. According to the Swedish guidelines for patient-centered care patients should be actively involved in decisions regarding their own care. To enable patients to exercise their autonomy, one has to provide relevant information as well as maintaining good communication. Arguably, this has not been achieved in cases where patients have experienced that they have not been listened to. Thus it can be argued that this kind of poor service involves lack of respect for patient autonomy.

A disrespectful encounter could also be interpreted as evidence that the caregiver does not see the patients as equals, and therefore does not grant them the dignity they are entitled to.

To sum up, one can say that a positive encounter meets the requirements of all four principles, while a negative encounter goes against one or more of them.

7 APPLICATION AND SUGGESTED POLICIES

Since negative healthcare encounters are arguably bad as such and are also related to factors such as delayed treatment, negative health outcomes and thereby loss in wellbeing, reduced trust in the healthcare system, and perceived delay in the patient's ability to return to work, I am convinced it is important to actively try to prevent or at least reduce them. The findings from the studies included in this thesis do not suggest specific practical methods to be used, but imply a number of potential strategies. Before taking action, one needs to know at what level to act. We propose that experiences of negative encounters can be explained by two general factors: *structure* and *individual behaviour and attitudes*. In order to do something about the problem one must first identify the level it stems from.

7.1 STRUCTURE

Changes in structure generally require policy decisions on a political or organizational level and often actualize the question of resource allocation. Changes in distribution of resources may affect the healthcare staff's work conditions and ability to carry out their activities with high quality, and thus how patients and their relatives perceive the healthcare encounter.

- Increased allocation of resources would enable healthcare to better meet and satisfy patients' requests for examinations and treatments. For example, it is likely that there would be fewer complaints about availability, short consultations, and stressed personnel if the workforce was expanded and more time could be allocated for each patient. Also, complaints about waiting time both in emergency care and when referring patients to specialists would probably decrease if more resources were calculated for each patient.

- If increased resources are not an option, one can try to better communicate the official priorities, which may make it easier for patients to assess whether they get the service they are entitled to, and on what grounds (which may lead them to perceive their healthcare encounters differently, though this cannot be guaranteed). Such information to patients may also have the positive effect of nurturing realistic expectations as to what patients will receive from the healthcare system in the future.

- How healthcare distributes information to patients in different contexts is largely a structural issue, although dissatisfaction with information is often perceived by the patient as an issue of poor communication skills on the part of a specific caregiver. In emergency care, for example, improved communication of information about the anticipated waiting time may be a structural measure for improvement. Routines for this have already been implemented in many healthcare settings, but there are still sites lacking this service, which means that there is room for improvement. This measure coupled with clear communication of priorities, I argue, would avert many complaints to do with distribution of care and waiting time. I base this view on previous findings presented in literature, as well as on the testimonies from participants in my studies (for example in study I), stressing that patients usually show understanding for adverse events, as long as they are given an excuse, or at least an explanation.[129]

7.2 INDIVIDUAL BEHAVIOUR AND ATTITUDES

How one behaves towards others may depend on deeply rooted convictions and habits but also on temporary circumstances such as trouble at home, lack of sleep, or momentary mood swings. Although potentially difficult to modify, healthcare encounters can be improved through education and training aiming at self-reflection and self-control.

- Training during medical education, nursing education, and other specialties should emphasize the importance of positive encounters in healthcare, and provide opportunities for the students to practise on this. One way of improving skills in the handling of patient encounters is to let students practise on each other in a fictional situation. Such practice can, for example, be documented by video recording and discussed afterwards by the participating students and their peers. If a self-reflective process is made part of the education, the students will be better prepared for their future meeting with patients.

- Training can also focus directly on successful communication. The students may benefit from basic knowledge about different models for communication,

and this way learn to adapt the information to the perceptional level and capability of different patients

- Continuous reflection and feedback on students' practical experiences from clinical situations may also influence behaviours and attitudes. This makes it important for the students' that supervisors or superiors actively monitor and support their professional development.

- Training in ethics may be a way to influence the attitudes of future healthcare professionals, in particular by stressing the importance of respectful treatment, including respect for autonomy and personal integrity. It is also a way to generally promote the students' capacity for critical and constructive reflection on their own and others' behaviour. In such training, one may choose to refer back to the main types of ethical theories (deontological theories, consequentialism, and virtue ethics) by emphasizing patient rights and ethical restrictions on what behaviour healthcare staff may subject patients to, by highlighting possible consequences of healthcare encounters and why they matters, and by discussing which personal characteristics, such as empathy, patience, sensitivity, being a good listener, and being guided by a desire to do good and not harm, are particularly desirable among medical staff for ensuring a positive encounter.

Apart from the structurally and individually adapted suggestions for policies, I also would like to take the opportunity to stress a few more things of relevance for handling and preventing future complaints, namely the need for supportive systems for reporting healthcare complaints and the importance of acknowledging that more and more healthcare encounters are "digital encounters".

7.2.1.1 *Supportive systems*

It is of great importance to develop and maintain efficient and supportive systems for reporting healthcare complaints. It is central to extend the accessibility of the service to all patients, and to ensure that no groups are excluded due, for example, to language skill shortcomings. Information in different languages, availability of interpreters, and proactive communication of the services to the patients and healthcare staff may be of

great relevance here. The system(s) should also be able to analyse and constructively use the reported complaints in continuous improvement of the healthcare experience.

7.2.1.2 *Digital encounters*

To an increasing extent, patients are interacting with healthcare by other means than physical (IRL) encounters. Advice, time booking, and renewal of prescriptions are already being handled by many people via the computer screen, touch pad, or Smartphone. Since there is an experience of an encounter with "the other side" regardless of whether the meeting takes place in real life or is digitally mediated, it is important that the insights from studies of interpersonal encounters should also be applied as guiding principles when designing and implementing e-health applications.

Arguably, the digital encounter has properties that can be more satisfying than the human encounter. Here are just a few examples: digital services are more available; bookings and cancellations are synchronized and easier to manage; information can be read and re-read, which lowers the risk of misunderstandings; you do not risk exposing your problems or worries to other patients or unauthorized staff (which may happen, for instance, in waiting rooms). An educated guess is that user-friendly and well-functioning interfaces will be perceived as positive digital encounters, while counter-intuitive and inert interfaces will be looked upon as negative encounters. Therefore, it is important to carefully consider what features and interaction design make patients perceive the interaction with healthcare through a digital interface as a positive encounter.

8 SIGNIFICANCE

As has already been thoroughly discussed, maintaining a standard of positive and respectful encounters in healthcare is important in its own right as well as for positive health outcomes and patients' trust in healthcare. The field of research regarding encounters in healthcare has expanded during the last decade but little is still known about the general population's experiences of negative encounters in healthcare. This thesis aimed at filling that gap. A solid empirical base is a precondition for a constructive debate about the occurrence and implications of positive and negative encounters in healthcare. It is also needed in order to accomplish fruitful changes. The aim of this project was to provide the relevant knowledge.

9 IMPLICATIONS FOR FURTHER RESEARCH

Interviews with patients feeling wronged

Interviews would be a natural next step in order to deepen our knowledge about patients who feel wronged in their healthcare encounters. This would enable us to better understand the mechanisms behind the experience of feeling wronged, and perhaps also to examine the contemporary use of language (discourse analysis) in order to find out if the increased use of the term may be due to linguistic changes. It would also be of interest to examine how men and women reason about their perceptions of being wronged.

Encounters and the idea of responsibility

It would also be interesting to explore encounters of certain specific patient groups, and the idea of responsibility. The question is whether the healthcare staff's own values and attitudes may sometimes affect the encounter of certain patients, for example patients with lung cancer or obesity, conditions that may be perceived as self-inflicted.
Values and attitudes may include perceptions of the patient's own responsibility for certain illnesses and which treatment interventions should be offered. The healthcare professionals' own values may conflict with official values in healthcare and could, if put into practice, mean some patient groups being discriminated against, stigmatized, or not receiving adequate medical treatment.

Impact of encounters and RTW

Previous studies have found associations between experiences of encounters and health outcomes. In a study related to this thesis, our research group also found evidence that experiences of negative encounters and feeling wronged are perceived as hindering the respondents (patients on sick-leave) from returning to work (RTW), while a positive encounter and the feeling of being respected (as opposed to feeling wronged) is perceived as facilitating the respondents RTW. However, it would be interesting to investigate whether there are actual differences in duration of sick-leave between these two groups. A proposed idea for a future study would therefore be to review the actual period of sick-leave for each respondent in relation to a questionnaire about factors having an impact on RTW.

10 CONCLUSION

This thesis concerns experiences of encounters in Swedish healthcare. A positive encounter in healthcare is important as such, but also because of the impact it may have on health outcomes, wellbeing, and trust in the healthcare system.

The focus of this thesis has been on negative experiences of encounters in healthcare. Being met with arrogance, disrespect, not being listened to, stressed personnel, and rude behaviour are some of the aspects of events that are perceived as a negative encounter.

We propose that experiences of negative encounters may be explained by two overarching explanatory factors: structure of the healthcare organization, and the staffs' attitudes and behaviour. Depending on which of the two factors underlies the experience, different strands of preventive measures are available.

Poor communication was also identified as a factor prevalent in many events of negative encounters, and is suggested as a main target for intervention. Good communication is likely to avert many complaints attributable to structure, but also complaints induced by inability of the healthcare staff to establish a well-functioning patient–caregiver relation adapted to the needs of the patient.

Only one out of seven respondents who claimed to have had reason to complain about negative encounters in healthcare had gone through with their complaint to Patientnämnden. We conclude that such adverse events are heavily under-reported and that knowledge of barriers to filing complaints should be used constructively when developing inclusive, supportive and safe systems for handling future healthcare complaints.

To improve patients' experiences of encounters in healthcare, several different strands of action have been suggested, including reallocation or increased resources, communication of official priorities, and improved information about waiting time at the sites. We also suggest practice in ethical reflection and self-reflection during medical education, practice of communication skills, and continuous support and supervision of the students' professional development.

This thesis has its point of departure in my personal experience of how people seem to relate to the subject of negative encounters on a personal level, and how they are often eager to discuss their own experiences of negative encounters in healthcare with me. Is their inclination to discuss these experiences perhaps grounded in not having felt listened to and confirmed during the healthcare encounter, and thus feeling driven to seek acknowledgment elsewhere? These people have generally not been seriously ill. On the contrary, their experiences often come from seeking care for minor ailments. The way I see it, this is yet another indication of how positive encounters are fundamental to what the patient expect from the healthcare service. For this reason, and all the reasons forest forth in this thesis, it is evident that research and interventions aimed at achieving positive encounters in healthcare need to be prioritized.

SVENSK SAMMANFATTNING

Att få ett gott bemötande i sjukvården är något som de allra flesta tycker är viktigt. Som patient eller närstående befinner man sig ofta i en utsatt ställning då man är försvagad på grund av sjukdom, men också på grund av en ojämn maktbalans mellan patient och vårdgivare ifråga om kunskap och tillgång till resurser. Av denna anledning är det av stor vikt att sjukvårdspersonal bemöter sina patienter med respekt och omsorg. Negativa erfarenheter av bemötande i sjukvården har kunnat kopplas till upplevda negativa hälsoeffekter, och kan påverka patientens förtroende för sjukvården.

Det övergripande syftet i denna avhandling var att bredda kunskapen om detta ämne, för att på så sätt möjliggöra en diskussion om potentiella strategier för att minska förekomsten av patienters upplevelser av dåligt bemötande i svensk sjukvård.

Avhandlingen består av fyra delstudier. Studie I är en registerstudie där klagomål till Patientnämnden har studerats, och studie II, III, och IV baseras på enkäter som handlar om upplevelser av bemötande i svensk sjukvård. Studie I och III har en huvudsakligen kvalitativ inriktning, medan studie II och IV i första hand är kvantitativa.

I Studie I utfördes en systematisk översikt av de klagomål på bemötande som under 2006 och 2007 anmälts till patientnämnden i Stockholm. Syftet var att undersöka vilka typer av negativa erfarenheter av bemötande som rapporterades. Innehållsanalysen visade att den vanligaste typen av klagomål handlade om oförskämt, aggressivt och arrogant bemötande, men klagomål på att ha känt sig ignorerad, inte bli tagen på allvar, samt inte bli lyssnad på var också vanligt förekommande. Ett intressant bifynd var att cirka en tredjedel av alla klagomål på medicinsk behandling som registrerats, också visade sig innehålla klagomål på dåligt bemötande. Kvinnor rapporterade oftare klagomål på dåligt bemötande än män.

Studie II baseras på en enkät som under 2004 gick ut till långtidssjukskrivna och som handlade om deras upplevelse av bemötande i sjukvården samt hos försäkringskassan. Det primära syftet var att undersöka förekomsten av olika typer av dåligt bemötande i sjukvåden samt vilken typ av bemötande som orsakade en känsla av att bli kränkt. Analysen visade att nonchalant och respektlöst beteende var starkt relaterat till känslan av att bli kränkt, men även att erfarenhet av att inte bli trodd, bli ifrågasatt, att inte bli lyssnad på, samt att bli behandlad som dum var kopplat till känslan av att bli kränkt. Analysen pekar mot att känslan av att ha blivit kränkt sällan orsakas av en separat upplevelse av dåligt bemötande, utan är en effekt av

ackumulerade negativa erfarenheter. Kvinnor rapporterade oftare erfarenhet av dåligt bemötande, men män rapporterade i högre grad att de känt sig kränkta då de hade utsatts för dåligt bemötande.

Studie III och IV utgår ifrån en enkät om upplevelser av negativt bemötande i sjukvården som utfördes bland befolkningen i Stockholm. Det primära syftet i studie III var att vidga förståelsen för negativa erfarenheter av dåligt bemötande genom att analysera deltagarnas egna beskrivningar av negativa erfarenheter antingen som patient eller som anhörig. Även i denna studie förkom beskrivningar av nonchalant och otrevligt beteende samt att inte bli lyssnad eller trodd på, men också klagomål på tillgänglighet, stressad personal, bristande information, eller att bli nekad undersökning eller behandling. Två möjliga underliggande faktorer till klagomål diskuteras: struktur och individuella attityder och beteenden. Beroende på vilken av dessa två faktorer som ligger bakom den negativa upplevelsen föreslås olika tillvägagångssätt för att förebygga framtida negativa erfarenheter. Studie IV fokuserar på möjliga underliggande faktorer till underrapportering av klagomål på negativet bemötande. Av 159 respondenter som uppgav att de hade haft skäl att anmäla ett klagomål så var det bara 23 personer som hade gått vidare och gjort en anmälan. Skälen som angavs för att inte anmäla var bland andra att man inte orkade, inte visste vart man skulle vända sig, eller att man ansåg att det ändå inte skulle göra någon skillnad. Erfarenheter av dåligt bemötande visade sig också vara relaterat till lägre förtroende för sjukvården.

Resultaten från studierna diskuteras slutligen utifrån hur de relaterar till tidigare kunskap och teorier, men även normativt utifrån ett perspektiv där fyra grundläggande principer om att göra gott, att inte göra ont, rättvisa, samt rätt till självbestämmande (autonomi) är vägledande. Slutligen presenteras ett antal potentiella strategier och åtgärder för att minska förekomsten av patienters upplevelser av dåligt bemötande i sjukvården, och på detta sätt skapa ett bättre, tryggare och mer effektivt sjukvårdsystem.

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11 REFERENCES

1. SKL. Statistik om hälso-och sjukvård samt regional utveckling 2011 (Statistics of healthcare and regional development 2011). Available at: https://www.skl.se/vi_arbetar_med/statistik/statistik_ekonomi/verksamhet_och_ekonomi_i_landsting_och_regioner/verksamhet-och-ekonomi-2011. Access date 1 May 2013

2. Holmberg S, Weibull L. Förtroendebarometern 2012 (The trust-survey 2012) MedieAkademin/TNS Sifo AB. Available at: http://medieakademin.welcom.se/pdf/fortroendebarometern_2012.pdf. Access date 27 Apr 2013

3. GfK Custom Research. GfK Trust Index for spring 2010. Available at: http://www.gfk.com/imperia/md/content/presse/pressemeldungen2010/100609_pm_trust_index_2010_efinal.pdf. Access date 27 Apr 2013

4. Stockholms läns landsting. Vården får närmare 45 miljarder i år. Nyhetsarkiv (Healthcare receives around 45 billion this year) 2011. Available at: http://sll.se/SLL/Templates/NewsPage.aspx?id=56032. Access date 31 Jan 2013

5. Patientnämnden årsrapport 2012 (Annual report 2012) Stockholm: Patientnämnden. Available at: http://www.patientnamndenstockholm.se/res/Arsrapport/Aarsrapport-2012.pdf. Access date 10 April 2013

6. Johansson M. Hälsa alltings mål? Funderingar kring det goda bemötandet (Health as the ultimate goal? Reflections about the positive encounter) in Goda möten i hälso – och sjukvården. Henrik Hammar symposium 2010. Region Skånes etiska råd. Lund: Media-Tryck Lunds Universitet. p. 81.

7. SFS 1982:763.Hälso och sjukvårdslag . Stockholm: Socialdepartementet

8. Bynum W. The history of medicine. A very short introduction. Oxford University Press: New York 2008. Chpt 1,3,6.

9. Stolt CM. Många banbrytande upptäckter – men också stora felbedömningar (Many groundbreaking discoveries, but also large miscalculations). Läkartidningen 1999;96:5744-52.

10. Hälso- och sjukvårdsnämnden. Årsredovisning 2011. Bilaga 2. Vad tycker medborgare och patienter om vården? Resultatredovisning från vårdbarometern och patientenkäterna (Annual report 2011. Appendix 2. How do the public and the patients perceive healthcare? Result report from the trust-survey and patient-surveys) Stockholm: Hälso- och sjukvårdsnämnden. Available at: http://www.sll.se/Handlingar/HSN/2012/(02)%2015%20februari/p%2003%20%C3%85rsredovisning%202011.pdf . Access date 20 Feb 2013

11. Lynoe N, Wessel M, Olsson D, Alexandersson K, Helgesson G. Respectful encounters and return to work: empirical study of long-term sick-listed patients' experiences of Swedish healthcare. BMJ Open 2011;1:e000246.

12. Svensson T, Müssener U, Alexanderson K. Pride, empowerment, and return to work: on the significance of promoting positive social emotions among sickness absentees. Work 2006;27:57–65.

13. Müssener U, Festin K, Upmark M, Alexanderson K. Positive experiences of encounters with healthcare and social insurance professionals among people on long-term sick leave. Journal of Rehabilitation Medicine 2008;40:805–11.

14. Sarafino E. Health Psychology – Biopsychosocial Interactions, 5th ed. Hoboken: John Wiley and Sons Inc.; 2006. p. 290-294.

15. Patientnämnden Årsrapport 2011 (Annual report 2011). Stockholm: Patientnämnden. Available at: http://www.patientnamndenstockholm.se/res/Arsrapport/Aarsrapport-2011.pdf. Access date 6 May 2013

16. Frykman J. Särbehandlad och kränkt (Discriminated and wronged) Stockholm: Folkhälsoinstitutet. 2005. Report Nb. 2005:49.

17. Brottsförebyggande rådet. Statistisk databas (Swedish National Council for Crime Prevention. Statistical Database). Stockholm: BRÅ. Available at: http://statistik.bra.se/solwebb/action/index Access date Feb 14 2013

18. Fler anmäler ärekränkning (More people report defamation). Göteborgsposten. Available at: http://www.gp.se/nyheter/sverige/1.1166205-fler-anmaler-arekrankning. Accessed 5 feb 2013

19. Lerner T. Hjälpt eller stjälpt? Anmälningarna bara toppen av ett isberg (Helped or hindered? The reports show only the tip of an iceberg). Dagens Nyheter. Available at: http://www.dn.se/insidan/insidan-hem/anmalningarna-ar-bara-toppen-pa-ett-isberg. Accessed 13 Feb 2013

20. Nordgren M. Att bli tagen på allvar betyder så mycket (To be taken seriously means so much). Dagens Nyheter. Available at: http://www.dn.se/insidan/insidan-hem/att-bli-tagen-pa-allvar-betyder-sa-mycket. Accessed 13 Feb 2013

21. Zaremba M. Vad var det som dödade herr B? (Who killed Mr B?). Dagens Nyheter. Available at: http://www.dn.se/kultur-noje/vad-var-det-som-dodade-herr-b Accessed 13 Feb 2013

22. Kaba R, Sooriakumaran P. The evolution of the doctor – patient relationship. International Journal of Surgery 2007;5:57-65.

23. Croona G, Jenner H. Om makt och jämlikhet i professionella relationer (Power and equity in professional relations). Tidskrift for Socialpædagogik . 2001:7.

24. Invandrare i vård och omsorg – en fråga om bemötande av äldre. Stockholm: Socialdepartementet; 1997 SOU 1997:76

25. Patienten har rätt. Stockholm: Socialdepartementet; 1997. SOU 1997:154

26. Bemötande av äldre. Stockholm: Socialdepartementet: 1997. SOU 1997:170

27. Lindqvists nia - nio vägar att utveckla bemötandet. Stockholm: Socialdepartementet; 1999. SOU 1999:21

28. Stockholms Läns Landsting. Framtidsplan för hälso- och sjukvården – första steget i utförandet. (Plan for the future of healthcare – step one). 2011 Stockholm: SLL Available at: http://www.sll.se/upload/Framtidsplan_f%C3%B6rsta_steget_20april.pdf. Access date 8 Mar 2013

29. Patientlag. Delbetänkande av patientmaktsutredningen. Stockholm: Socialdepartementet. 2013. SOU 2013:2.

30. Miller S. Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease. Cancer 1995;76:167–77.

31. Sarafino E. Health Psychology – Biopsychosocial Interactions, 5th ed. Hoboken: John Wiley and Sons Inc., 2006. p 290-91.

32. SFS 1998:1656 om patientnämndsverksamhet mm. Stockholm: Socialdepartementet.

33. Patientnämndens årsrapport 2010 (Annual report 2010). Stockholm: Patientnämnden. Available at: http://www.patientnamndenstockholm.se/res/Arsrapport/Aarsrapport-2010.pdf. Access date 6 May 2013

34. Kuosmanen L, Kaltiala-Heino R, Suominen S, Kärkkäinen J, Hätönen H, Ranta S, et al. Patient complaints in Finland 2000-2004: a retrospective register study. Journal of Medical Ethics 2008;34:788-92.

35. European Observatory on health systems and policies. Assuring the quality of healthcare in the European Union. A case for action. Observation Studies Series No. 12. 2008. p. 100-11. Available at: http://www.euro.who.int/__data/assets/pdf_file/0007/98233/E91397.pdf. Access date 6 March 2013

36. Helse- og omsorgsdepartementet. Statens helsetillsyn. Årsrapport 2012 (Health audit, annual report 2012) Available at:

http://www.helsetilsynet.no/upload/Publikasjoner/aarsrapporter/aarsrapport2012.pdf. Access date 6 Mar 2013

37. Müssener U. Encouraging encounters. Experiences of people on sick leave in their meetings with professionals. Doctoral Thesis. Division of Social Medicine and Public Health, Department of Health and Society. Linköping University. 2007. p. 40.

38. Östlund G, Borg K, Wide P, Hensing G, Alexanderson A. Clients´ perceptions of contact with professionals within healthcare and social insurance officers. Scandinavian Journal of Public Health 2003;31(4):275-82.

39. Östlund G. Alexanderson K. Cedersund E, Hensing G. It was really nice to have someone"; Lay people with musculoskeletal disorders request supportive relationships in rehabilitation. Scandinavian Journal of Public Health 2001;29:285-91.

40. Westin L, Danielsson E. Encounters in Swedish nursing homes: a hermeneutic study of residents' experiences. Journal of Advanced Nursing 2007;60(2): 172-80.

41. Croona G. Bemötandeproblematiken i vården – hur kan vi förstå den? (Problematic encounters –how can we understand it?) Vårdförbundet Halland 2011. Available at: https://www.vardforbundet.se/Documents/V%C3%A5rdfokus/Gill%20Croona%20bem%C3%B6tande.pdf. Access date 25 Apr 2013

42. Upmark M, Borg K, Alexanderson K. Gender differences in experiencing negative encounters with healthcare: A study of long-term sickness absentees. Scandinavian Journal of Public Health 2007;35:577-84.

43. Söderberg S, Olsson M, Skär L. A hidden kind of suffering: female patient's complaints to Patient's Advisory Committee. Scandinavian Journal of Caring Science. 2012;26(1):144-50.

44. Osika I. Jämställda klagomål (Equal complaints). 2006. Stockholm: Stockholms läns landsting. Avalable at http://www.sll.se/Page/32704/klagomal.pdf. Access date 7 May 2013

45. Birkler J. Filosofi och omvårdnad. Etik och människosyn (Philosophy and nursing. Ethics and humanity). Stockholm: Liber AB 2007. p. 60-68.

46. Bäärnhielm S. Möten i den mångkulturella vården (Encounters in a multi-cultural healthcare). In Fossum B, editor. Kommunikation. Samtal och bemötande i vården (Communication. Conversations and encounters in healthcare). Lund: Studentlitteratur. 2007. p. 288-89.

47. Smirthwaite G.(O)jämställdhet i hälsa och vård – en genusmedicinsk kunskapsöversikt ((In)equality in healthcare – a review of gender in medicine). Stockholm: Sveriges kommuner och landsting. 2007 available at: http://jamda.ub.gu.se/bitstream/1/357/1/genusmed.pdf. Access date 5 May 2013

48. Stewart M. Effective physician-patient communication and health outcomes: a review. Canadian Medical Association Journal 1995;152:1423-33.

49. Jangland E. Cunningberg L, Carlsson M. Patients' and relatives' complaints about encounters and communication in healthcare: evidence for quality improvement. Patient Education & Counseling 2009 May;75(2):199-204. doi: 10.1016/j.pec.2008.10.007.

50. Taylor D. Wolfe R, Cameron P. Complaints from emergency department patients largely result from treatment and communication-problems. Emergency Medicine 2002;14:43-49.

51. Ong L. Haes J. Hoos A, Lammes F. Doctor-patient communication: a review of the litterature. Social Sciences & Medicine 1995;40:903-18.

52. Rosenstein A, O´Daniel M. A survey of the impact of disruptive behaviours and communication defects on patient safety. Joint Commission Journal on Quality and Patient Safety 2008;34:464-71.

53. Vincent CA, Coulter A. Patient safety: what about the patient? BMJ Quality & Safety 2002;11:76-80.

54. Zolnierek K, Dimatteo M. Physician Communication and patient adherence to treatment: a meta-analysis. Medical Care 2009;47:826-34.

55. Pinto R, Ferreira M, Oliveira V, Franco M, Adams R, Maher C, Ferreira P. Patient-centred communication is associated with positive therapeutic alliance: a systematic review. Journal of Physiotherapy 2012;58(2):77-87.

56. Vermeire E, Hearnshaw H, Van Royen P, Denekens J. Patient adherence to treatment: three decades of research. A comprehensive review. Journal of Clinical Pharmacy and Therapeutics 2001;26:331-42.

57. Lee Y, Lin J. Linking patients' trust in physicians to health outcomes. Brittish Journal of Hospital Medicine 2008;69:42-46.

58. Hojat M, Louis D, Markham F, Wender P, Rabinowitz C, Gonnella J. Physicians' empathy and clinical outcomes for diabetic patients. Academic Medicine 2011;86:359-64.

59. Ciechanowski P, Katon W, Russo J, Walker E. The patient-provider relationship: attachment theory and adherence to treatment in diabetes. American Journal of Psychiatry. 2001;158: 29-35.

60. Halldórsdóttir S, Hamrin E. Caring and uncaring encounters within nursing and healthcare from the cancer patient's perspective. Cancer Nursing 1997:20(2):120-28.

61. Tod AM, Craven J, Allmark P. Diagnostic delay in lung cancer: a qualitative study. Journal of Advanced Nursing Nursing 2008;61:336-43.

62. Olsson B, Olsson B, Tibblin G. Effect of patients' expectations on recovery from acute tonsillitis. Family Practice 1989;6:188-92.

63. Kaplan S, Greenfield S, Ware J. Assessing the effects of physician–patient interactions on the outcomes of chronic disease. Medical Care 1989;27(3):110-27.

64. Schnitzer S, Kuhlmey A, Adolph H, Holzhausen J, Schenk J. Complaints as indicators of healthcare shortcomings: which groups are affected? International Journal for Quality in Healthcare 2012:24(5):476-82.

65. Gijsberg van Wijk C, van Vilet K, Kolk A. Gender perspectives and quality of care: Towards appropriate and adequate healthcare for women. Social Science & Medicine 1996;43(5):707-20.

66. Arman M, Rehnsfeldt A, Lindholm L, Hamrin E, Eriksson K. Suffering related to healthcare: a study of breast cancer patients' experiences. 2004;10(6):248-56.

67. Doyal L. Sex, gender, and health: the need for a new approach. BMJ 2001;323 doi: http://dx.doi.org/10.1136/bmj.323.7320.1061

68. Im E, Meleis A. An international imperative for gender-sensitive theories in women´s health. Journal of Nursing Scholarship 2001;33(4):309-14.

69. Pukk K, Lundberg J, Penazola-Pesantes R, Brommels M, Gaffney A. Do women complain more? National patient injury claims data show gender and age differences. Quality Management in Healthcare. 2003;12(4):225-31.

70. Lee TH. Gaps in quality of cardiovascular care transcend social bias. Circulation 2000;102:943–44.

71. Lydiatt DD. Medical malpractice and cancer of the larynx. Laryngoscope. 2002;112:445–48.

72. Kjellstrand CM, Logan GM. Racial, sexual and age inequalities in chronic dialysis. Nephron 1987;45:257–63.

73. Turk-Charles S, Meyerowitz B, Gatz M. Age differences in information-seeking among cancer patients. International Journal of Aging and Human Development. 1997;45:85-98.

74. Woodward N, Wallston B. Age and health care beliefs: Self-efficacy as a mediator of low desire for control. Psychology and Aging. 1987;2:3-8.

75. Nationell Patientenkät. Primärvård höst 2010. Läkarbesök (National Survey. Primary Care 2010. Healthcare visits) Vänersborg: Hälso –och sjukvårdsnämnden Västra götalandsregionen. Available at : http://www.vgregion.se/upload/Regionkanslierna/hsskansli/Analys/Rapporter/2011/Nationell%20patientenk%C3%A4t%20prim%C3%A4rv%C3%A5rd%20h%C3%B6st2010%202.pdf. Access date 15 March 2013

76. Carlsson F, Merlo J, Lindström M, Östergren P-O, Lithman T. Representativity of a postal public health questionnaire survey in Sweden, with special reference to ethnic differences in participation. Scandinavian Journal of Public Health 2006;34(2):132-39.

77. Patientenkät och vårdbarometern (Patient survey and the Health barometer). Stockholm: Sveriges kommuner och landsting. Available at: http://www.skl.se/MediaBinaryLoader.axd?MediaArchive_FileID=1afd3a28-ca09-46b1-a3ff-97c75f752ba4&FileName=J%C3%A4mlik+v%C3%A5rd+PM+2012-06-05+(slutversion).pdf. Access date 30 April 2013

78. Sundquist J. Ethnicity as a risk factor for consultations in primary healthcare and out-patient care. Scandinavian Journal of Primary Healthcare 1993;11:169-73.

79. Larsen J-H. Besvaerlige patienter (Difficult Patients). Kobenhavn: Borgen, 1981 p.170-176.

80. Lin E, Katon W, Von Korff M, Bush T, Lipscomb P, Russo J, et al. Frustrating patients: physician and patient perspectives among distressed high users of medical services. Journal of General Internal Medicine 1991, 6:241-46.

81. Kroenke K. Patients presenting with somatic complaints: epidemiology, psychiatric co-morbidity and management. International Journal of Methods in Psychiatric Research 2003:12(1);34-43.

82. Sharpe M, Mayou R, Seacroatt V, Surawy C, Warwick H, Bulstrode C, et al. Why do doctors find some patients difficult to help? Quarterly Journal of Medicine. 1994; 87:187-93.

83. Hahn S, Kroenke K, Spitzer R, Brody D, Williams J, Linzer M, et al. The difficult patient in primary care: prevalence, psychopathology and impairment. Journal of General Internal Medicine 1996; 11: 1–8.

84. Hahn S, Feiner J, Bellin E. The doctor-patient-family relationship: a compensatory alliance. Annals of Internal Medicine 1988;109:884–89.

85. Fernandez Y, Garcia E, Duberstein P, Paterniti D, Cipri C, Kravitz R, et al. Feeling labeled, judged, lectured, and rejected by family and friends over depression: Cautionary results for primary care clinicians from a multi-centered, qualitative study. BMC Family Practice 2012;13:64. doi: 10.1186/1471-2296-13-64

86. Lynøe N, Wessel M, Olsson D, Alexanderson K, Tännsjö T, Juth N. Duelling with doctors, restoring honour and avoiding shame? A cross-sectional study of sick-listed patients' experiences of negative healthcare encounters with special reference to feeling wronged and shame. Journal of Medical Ethics doi:10.1136/medethics-2012-100871

87. Hall J. Roter D, Milburn M, Daltroy L. Patients' health as a predictor of physician behaviour in medical visits: a synthesis of four studies. Medical Care 1996:34;1205-18.

88. Engblom M, Alexandersson K, Rudebeck C-E. Characteristics of sick-listing cases that physicians consider problematic – analyses of written case reports. Scandinavian Journal of Primary Healthcare 2009;27(4):250-55.

89. Maeland S, Werner E, Rosendal M, Jonsdottir I, Magnussen L, Ursin H, et al. Diagnoses of patients with severe subjective health complaints in Scandinavia: a cross sectional study. ISRN Public Health, vol. 2012 (2012) doi:10.5402/2012/851097

90. Lynoe N, Juth N. Medicinska etikens ABZ. Stockholm: Liber AB 2009

91. Tännsjö, Torbjörn, Grundbok i normativ etik. Stockholm: Thales 2003. p 16-17

92. The American Heritage Dictionary of the English Language (4th ed.). "Empirical research". Boston: Houghton Mifflin. 2000

93. Van der Scheer L, Widdershoven G. Integrated empirical ethics: loss of normativity? Medicine Healthcare and Philosophy 2004:7;71-79.

94. Weaver G, Trevino L. Normative and empirical business ethics: separation, marriage of convenience, or marriage of necessity? Business Ethics Quarterly 1994:4(2);129-43.

95. Beauchamp T, Childress J. Principles of biomedical ethics 5th ed. Oxford University Press: Oxford 2001.

96. Beauchamp T, Childress J. Principles of biomedical ethics 5th ed. Oxford University Press: Oxford 2001. p. 12-23.

97. Dawson A, Gerrard E. In defence of moral imperialism: four equal and universal prima facie principles. Journal of Medical Ethics 2006;32:200-04.

98. Helgesson G. Forskningsetik för medicinare och naturvetare (Research ethics in medicine and natural sciences). Lund: Studentlitteratur 2006. p 60.

99. Nationalencyklopedin (NE) online. "Bemötande" Available at: http://www.ne.se/sve/bem%C3%B6tande?i_h_word=bem%C3%B6tande. Access date 20 March 2013

100. Fossum B. Kommunikation. Samtal och bemötande i vården (Communication. Conversations and encounters in healthcare). Lund: Studentlitteratur 2007. p. 31.

101. Silverman D. Qualitative Research: Theory, Method and Practice. London: SAGE Publications, 2004. Chpt. 2.

102. Müssener U, Söderberg E, Svensson T, Alexanderson K. Encouraging encounters: sick-listed persons' experiences of interactions with rehabilitation professionals. Social Work in Healthcare 2008;46(2)71-87.

103. Klanghed U, Svensson T, Alexanderson K. Positive encounters with rehabilitation professionals reported by persons with experience of sickness absence. Work, 2004;22:247-54.

104. Rockhill B, Newamn B, Weinberg C. Use and misuse of population attributable fractions. American Journal of Public Health 1998;88:1.

105. Lehnert-Batar A. Pfahlberg A, Gefeller O. Comparison of confidence intervals for adjusted attributable risk estimates under multinominal sampling. Biometrical Journal 2006;48(5):805-19.

106. Benichou J. A review of adjusted estimators of attributable risk. Statistical Methods in Medical Research 2001;10:195-216.

107. Faherty V. Wordcraft: Applied Qualitative Data Analysis (QDA): Tools for Public and Voluntary Social Services, Thousand Oaks: SAGE Publications, California 2009. Chpt 4.

108. Hseigh H-F, Shannon S. Three approaches to qualitative content analysis. Qualitative Health Research 2005;15:1277-88.

109. Krippendorff K. Content analysis. An introduction to its methodology. 2nd ed. Thousand Oaks, California: Sage Publications Inc. 2004. p. 208-10.

110. Malterud K. Kvalitativa metoder i medicinsk forskning (Qualitative methods in medical research). Lund: Studentlitteratur. 2009. p.179-88.

111. Patel R, Davidsson R. Forskningsmetodikens grunder (Basics of research methodology) 3rd ed. Lund: Studentlitteratur. 2003. p.98-106

112. Trost J. Enkätboken (The book about surveys). Lund: Studentlitteratur. 1994. p. 53-59.

113. Marshall C, Rossman G. Designing Qualitative Research. 4th ed. SAGE Publications: Thousand Oaks, California. 2006. p. 125-26.

114. Patel R, Davidsson R. Forskningsmetodikens grunder (Basics of research methodology) 3rd ed. Lund: Studentlitteratur. 2003. p.55.

115. Japec L, Ahtiainen A, Hörngren J, Lindén H, Lyberg L, Nilsson P. Minska bortfallet (Reduce drop out) Statistiska centralbyrån. Örebro: SCB-Tryck. 1997. p 120-25.

116. Peeters G, Czapinski J. Positive-negative asymmetry in evaluations: The distinction between affective and informational negativity effects. In Stroebe W, M Hewstone, editors. European review of social psychology. New York: Wiley 1990 p.33-60.

117. Baumeister R, Bratslawsky E, Finkenauer C. Bad is stronger than good. Review of general Psychology 2001;5:323-70.

118. Patel R, Davidsson R. Forskningsmetodikens grunder (Basics of research methodology) 3rd ed. Lund:Studentlitteratur. 2003. p. 53.

119. Trost J. Enkätboken (The book about surveys). Lund: Studentlitteratur. 1994. p. 84.

120. Barach P, Small S. Reporting and preventing medical mishaps: lessons from non-medical near miss reporting systems. BMJ 2000;320:759-63.

121. Lawton R, Parker D. Barriers to incident reporting in a healthcare system. Quality and Safety in Healthcare 2002;11:15-18.

122. Christiaans-Dingelhoff I, Smits M, Zwaan L, Lubberding S, van der Wal G, Wagner C. To what extent are adverse events found in patient records reported by patients and healthcare professionals via complaints, claims and incident reports? BMC Health Services Research 2011;11:49. doi:10.1186/1472-6963-11-49

123. Olsen S, Neale G, Schwab K, Psaila B. Patel T, Chapman E, et al. Hospital staff should use more than one method to detect adverse events and potential adverse events: incident reporting, pharmacist surveillance and local real-time record review may all have a place. Quality and Safety in Healthcare 2007;16:40–44.

124. Räty L, Gustafsson B, Emotions in relation to healthcare encounters affecting self-esteem. The Journal of Neuroscience Nursing: Journal of the American Association of Neuroscience Nurses 2006;38(1):42-50.

125. Boyle D, Dwinnel B, Platt F. Invite, listen, and summarize: a patient-centered communication technique. Academic Medicine 2005;80:29-32.

126. Hall, J. Milburn M. Why are sicker patients less satisfied with their medical care? Tests of two explanatory models. Health Psychology 1998;17:70-75.

127. Foss C, Hofoss D. Patients' voices on satisfaction; unheeded women and maltreated men? Scandinavian Journal of Caring Sciences 2004;18:273-80.

128. Beauchamp T, Childress J. Principles of biomedical ethics 5th ed. Oxford University Press: Oxford 2001. p. 283-285.

129. Malterud K, Thesen J. When the helper humiliates the patient: a qualitative study about unintended intimidations. Scand Journal of Public Health 2008;36:92-98.

130. Johnsson L, Helgesson G, Hansson M, Eriksson S. Adequate trust avails, mistaken trust matters: on the moral responsibility of doctors as proxies for patients' trust in biobank research. Bioethics 2012 Jun 10 doi: 10.1111/j.1467-8519.2012.01977

131. Thom D, et al. Patient trust in the physician: Relationship to patient requests. Family Practice 2002;19:476-83.